

**U.S. Public Health Service
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities**

**Records of the Meeting of the
National Task Force on
Fetal Alcohol Syndrome and Fetal Alcohol Effect
December 6-7, 2004**

**Meeting held at the
Westin Buckhead Atlanta Hotel
Atlanta, Georgia**

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**National Center for Birth Defects and Developmental Disorders
National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect
December 2004 Meeting**

Meeting Summary

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was held on December 6-7, 2004, in Atlanta, Georgia.

Over the past two years, this Task Force has focused its efforts on developing criteria for FAS referral and diagnosis. While activities related to this work will continue, it is now important to focus time and efforts on prevention. To prepare for these discussions, this meeting will review the epidemiology of women and alcohol, what prevention strategies work, the effects of alcohol advertising on youth, and the challenges of moving prevention research into practice.

Women and Alcohol: What Do the Data Tell Us? Dr. Raul Caetano provided census-based and epidemiological information on women of childbearing age, births, and pregnancies in the U.S.; (2) described the epidemiological data (using the National Epidemiological Survey on Alcohol-Related Conditions – NESARC) on alcohol consumption among pregnant and non-pregnant women; and (3) briefly discussed approaches to prevention. Data from the NESARC, presented by Dr. Caetano, offer estimates on alcohol use, abuse, and dependence for women of childbearing age. In his analysis of pregnant women, Dr. Caetano found (1) pregnant women, 21-29 years of age, were more likely to be heavy drinkers, (2) those who were single or never married were 2 to 4 times more likely to be heavy drinkers, (3) the risk of heavy drinking rises with income, and (4) White women were more likely to be at risk than Blacks, Hispanics and Asians.

To prevent FAS-affected pregnancies, four activities are necessary: 1) surveillance (to determine the size of the problem); 2) identification of risk factors, and 3) evaluation of intervention effectiveness among groups; and 4) implementation. Levels of prevention when alcohol is a risk factor include universal, selective, and indicated strategies. Dr. Caetano presented a funnel diagram to show the different levels of risk (abstainer, low risk, drinkers who drink 4+, abusers, dependent) at each stage of the funnel and the prevention strategies relevant at each stage. The model moves the largest part of the funnel -- universal interventions (reduce availability), to selective interventions (screening, counseling, brief intervention), to indicated interventions (intervention, treatment) – the smallest segment of the funnel. Dr. Caetano proposed that most of the population follows a gradual progression from abstainer to high risk. He proposed that one way to proceed is to begin with universal interventions across the continuum from abstinence to initial drinking and then onward. The interventions would begin with strategies such as reduced availability of alcohol, with all other interventions coming later.

Discussion: It was suggested that another group at high risk, not included within the funnel diagram, are children offered alcohol at an early age to reduce their resistance to

sexual abuse. Also noted was that FAS is not generally a problem of young drinkers, and the likelihood that limiting alcohol availability would be challenged. However, the success of such bans relative to other outcomes such as car crashes can also support their use.

What Works? An Overview of Effective Prevention Strategies: Dr. Thomas Babor, from the University of Connecticut and a member of the Alcohol Public Policy Group (APPG), presented findings from the report, *Alcohol: No Ordinary Commodity*. This report outlines new developments in epidemiological research, growth of the knowledge base on policy-related strategies and interventions, and new understandings of the policymaking process at the local, national and international levels. Reviewers found evidence sufficient to support 31 strategies and interventions, which were subclassified to seven categories: regulating alcohol's physical availability, pricing and taxation; modifying the drinking context, education and persuasion, regulation of alcohol promotion, drinking-driving countermeasures, and treatment and early intervention.

Each of the prevention strategies or interventions was rated on a 4-point scale. Strategies were assessed on evidence of effectiveness (quality of scientific information); breadth of research support (quantity/consistency of the evidence); tested across cultures, and cost to implement the strategy. Evaluation standards also included consideration of the target groups, adverse side effects, population reach, and feasibility. Dr. Babor provided examples of strategies within each of the seven categories and offered the best and less-effective practices within these.

Dr. Babor proposed the following strategies as best practices: minimum legal age purchase regulations, government monopoly of retail sales, restricted hours or days of sales, outlet density restriction, alcohol taxes, sobriety check points, lowered BAC limits, administrative license suspension, graduated licensing for novice driver, and brief interventions for hazardous drinkers.

Less effective ("worst") practices listed were not to imply that some things, such as warning labels are not good or should be abandoned. However, the best practice strategies should be considered first. The least effective practices, based on review of the literature, include: voluntary codes of bar practice, promoting alcohol-free activities, alcohol education in schools, college student education, public service messages, warning labels, designated drivers and ride services

The cost-effectiveness of different policy options were outlined, as studied and modeled by the WHO in terms of years of functional life lost, or Disability Adjusted Life Years (DALY). Dr. Babor reviewed what the WHO had shown to be the most cost-effective strategies to prevent years of functional life lost. Ranking best in low costs and high impact was alcohol-related taxes, followed by advertising bans, reduced access, general practitioner advice and random breath testing. There are now more effective, evidence-based alcohol policies than ever to better serve the public good. Data indicate that policies limiting access to alcoholic beverages, increasing the price of alcohol, and enforcing laws and regulations through deterrence, are likely to reduce the harm linked to specific drinking patterns and per capita consumption. Alcohol problems can be

minimized or prevented using a coordinated, systematic policy response.

Alcohol Advertising and Adolescent Girls: Dr. David Jernigan, of Georgetown University's Center on Alcohol Marketing and Youth (CAMY), presented on this topic. Commonly available data show little progress over the last 12 years in reducing underage drinking. Eighth and tenth grade girls surpassed boys for the first time in 2002 as "current drinkers" and ninth grade girls lead boys in drinking more alcohol and binge drinking. The consequences of youth drinking are serious. Alcohol plays a key role in the three leading causes of death among young people: unintentional injuries (includes motor vehicle accidents), suicide and homicide. A CAMY survey of parents indicates that parents' perception of their teens' involvement with alcohol is very different from the teens' reported behaviors, suggesting that parents are unaware of this very serious issue in their children's lives.

The underage youth market accounts for 12-20% of the U.S. alcohol market and is dominated by heavy drinking. Research indicates that youth exposure to alcohol advertising increases awareness of the advertising and influences young people's beliefs about drinking and drinking behaviors. Adherence by the alcohol industry to its own self-regulation codes has been poor. Dr. Jernigan shared excerpts from the industry codes followed by actual advertisements that refute what the code outlines. CAMY was set up to monitor the marketing practices of the alcohol industry, particularly how they affect the health and safety of young people.

CAMY reports indicate that while beer and distilled spirits alcohol advertising typically targets the 21-34 year old age group, the advertisements were spilling over to younger rather than older groups. When compared to adults 21 and older, youth 12-20 saw per capita (1) 45% more beer ads and 12% more distilled spirit ads, (2) 65% more ads for alcopops and malternatives (e.g., Smirnoff Ice), and (3) 69% less wine ads. Data analysis revealed that the fewer number of wine ads suggest that the target populations can be reached without targeting youth directly. Research also indicates that girls are much more overexposed to alcohol advertising than boys, which has certain implications for FAS prevention.

Preliminary data (2004) on youth exposures to radio were presented and demonstrated heavier exposure for girls when compared to women than boys when compared to men. Data also show that minority groups are exposed to more alcohol advertising when compared to all other youth. Further research is needed to evaluate other marketing techniques, such as product placement; sponsorships; spring break, campus and sports marketing; and point of purchase advertising.

Dr. Jernigan provided information on the 2003 IOM report "*Underage Drinking, a Collective Responsibility*". This report proposed that the alcohol industry work towards a 15% maximum youth audience composition for their TV advertising; that DHHS regularly monitor underage exposure to alcohol advertising and report findings to Congress annually; that DHHS collect brand data through underage drinking surveys and that there should be a national media campaign about underage drinking to

educate adults about the problem. The Sober Truth On Preventing (STOP) Underage Drinking Act, which received bipartisan support, included several of the recommendations outlined in the IOM report. Legal research to defend against First Amendment defenses by the advertising community is underway and is supported by the National Association of Attorneys General. Dr. Jernigan also described some examples of state and local level alcohol advertising reforms (e.g., no alcohol advertising at sports events, bus shelters, family events). Funding and data licenses for CAMY are due to end in December 2004; however, funding has been extended to complete its work.

Discussion items included:

- Media literacy (training on how to critically examine advertisements and other kinds of media) is a valuable strategy, but it is insufficient by itself. Further evaluation of its effectiveness is needed.
- The Task Force was urged to shift the focus of FAS prevention beyond the individual woman involved to the social context that breeds the problem, and then to emphasize society's responsibility to prevent FAS.
- Dr. Hacker described a campaign implemented by the Center for Science in the Public Interest to remove advertising from sports television. College sports is the first step in this. Leading collegiate teams' coaches support this.
- More research is needed to determine whether the increased overexposure of young women is paralleled by an increase in FASD. The introduction of "alcopops" and rising rates of advertising provide a "natural experiment" for this.
- A question was asked if reducing underage exposures could be done without also reducing the advertising to the older age group. Dr. Jernigan responded that television will be the toughest arena in which to work due to the wide array of programming. It is also possible to reduce magazine ads. Research on specific brands of alcohol could help to target efforts.
- Recent industry attention to the social versus individual perception of responsibility for alcohol abuse indicates their understanding (although officially denied) of the association between advertising and consumption.
- The literature on alcohol policies indicates that the most effective interventions tend to be unpopular; and the least effective (individually oriented and based on simple interventions), popular. It is more likely that the social environment, product access, and the modeling presented to young women as a social group, are more important contributors than information on rare events, such as FAS. If the balance is to be altered, attention must first be paid to the evidence for the effectiveness of population-level approaches.
- The point was made that alcohol is not just a problem in the U.S. but a worldwide problem, yet little attention is paid to it internationally.
- Dr. Sokol called for this Task Force's attention to risk drinking (not all drinking) from both the individual consumer and the health professional perspective.

Moving Research into Practice: Kristen L. Barry, PhD, from the University of Michigan Department of Psychiatry and National Serious Mental Illness Treatment Research and Evaluation Center, discussed the challenges of moving alcohol research into practice. She outlined a spectrum of interventions that have been developed to address different patterns of alcohol use. Different interventions are appropriate based on an individual's level of use (e.g., light to moderate drinker vs. drinker with alcohol problems or mild dependence).

Data indicate that ~5-15% of women of childbearing age have some problems with alcohol use, as do 5.3% of 18-24 year-olds; 3.4% of women aged 25 years binge drank 5 or more times in the last 30 days; 12% of pregnant women drank in last month (SAMHSA, 2002).

Dr. Barry's study of pregnant women and alcohol use showed that 15% had used alcohol in pregnancy. Only half of pregnant women who drank reported that their physician talked about their alcohol use. Physicians were most likely to speak to women about alcohol use who were from low-income, minorities, and women with less education. Providers are slow to implement evidence-based screening or behavior interventions in part due to lack of time available and lack of knowledge about screening and intervening with women. Issues raised for the Task Force's consideration of recommendations on implementing interventions included: who and where to screen; addressing co-morbidities; why types of interventions (targeted research is needed); training of health care providers; advertising, laws and legal restrictions; and the reimbursement system. The research on intervention benefits and cost analyses were outlined, as were the new directions emerging for screening and brief interventions.

Discussion of Defining the FASD Prevention Agenda included the following:

- There is no established dose-response relationship. Binge drinkers are at most risk, but some research also indicates that even lower amounts of alcohol at particular times in pregnancy will produce a differing spectrum of disorders. Some contend that any drinking in pregnancy, even at low levels, can produce some cognitive deficits over time.
- Human research indicates a clinical teratology very similar to that in animals. Heavier drinking produces a greater proportion of those affected and has more effect. In that regard, FASD is a very useful concept to reflect the continuum of exposure causality.
- Another policy factor to consider is the varying susceptibility between individuals (and fetuses). The continuum of alcoholism has to extend all the way down to abusing drinking. An intervention's focus will have to be on where the effect is desired. Suggestions included:
 - Begin interventions prior to conception where there is high prevalence of adverse outcomes (but these are also the hardest people to impact).
 - Conduct selective interventions among those drinking or at risk of drinking.
 - Rather than focusing on either end the wedge, look at this broadly and

develop a multifaceted approach (e.g., strategies for the dependent and abusing drinker, as well as binge drinkers and those in the low risk category who may have a child with partial FAS).

- NIH's NESARC research data indicate that alcohol dependence is a developmental disorder which begins for many at age 15 and then peaks at 18 and again at 21. The brain continues to develop to age 21 so alcohol also impacts the brain in adolescence and young adulthood. NIAAA is currently researching this.
- Many trained professionals do not want to screen in the absence of treatment referral sources (e.g., for the alcohol abusing college student). Few state-level treatment services of women abusing or dependent on alcohol exist; of those, few address only alcoholism and most are geared to men. Few enroll women and fewer still accept women with children, pregnant or not.
- It was suggested that the Task Force consider outcomes that reflect real progress, such as a decline in the reported drinking in pregnancy coupled with lowered incidence of full FAS. Existing data gathering and tracking instruments (e.g., CDC's PRAMS program) could assess that. Washington state offers a good model for this.
- The importance of family history when assessing women for alcoholism or alcohol dependency was stressed, especially since the latter is not evident until the middle stages of the disease. Greater emphasis is needed in the literature that alcoholism is a disease. While it is important to examine alcohol use as a systemic, societal problem, the women at highest risk should not be overlooked.
- There is a spectrum of drinking patterns in which few women develop into full alcoholics. The disability spectrum resulting from alcohol use is important, but the most efficient use of resources remains a priority. We need to better understand the different risk groups, determine how to identify and reach these groups, and better understand factors related to successfully intervening. Outreach needs will vary.
- A matrix of risk groups and interventions could help begin the identification of interventions to different populations. The Task Force should not only recommend, but also indicate how to implement the selected interventions.
- Members recognized the need for multi-level strategies, especially those with the best evidence at different levels of alcohol use; and for better and earlier identification of alcoholics by physicians.
- Establishing a level or pattern of drinking as a marker that would indicate certain types of intervention (e.g., a matrix outlining different levels of drinking frequency to define those in the at-risk, abuse and dependent categories) was discussed. Either a positive T-ACE or above-normal quantity/frequency information, using NIAAA criteria, could be used to identify women at risk.

How to prioritize target groups and interventions was discussed. Some interventions, such as those with more palatable political and economic costs, could rise to the top. Some may be more likely to impact the population or effect outcomes. Which should be addressed first, or should this should be done comprehensively? Comments related to this included:

- Attention to Dr. Babor's list of best practices, but also to media challenges, social

issues, depression, and the sexual abuse that leads to abusive drinking.

- Server training interventions with women were considered unlikely to be successful.
- College students' binge drinking is not outlined in the Best Practices list but it is an important issues needing attention. Also, the need to educate men about the dangers of alcohol use should be included.
- It is important that the Task Force has a pragmatic review of the proposed best practices. For example, capacity building at the state level will be critical for successful implementation of Task Force recommendations.

Discussion with Dr. Babor focused on whether the Task Force should address women of childbearing age in general or on those most likely to be at risk. Dr. Babor indicated that focus should be on: women with alcohol dependence; women who periodically abuse alcohol or harmful drinking; women who exceed NIAAA or USDA guidelines for harmful drinking, and women who are likely to become pregnant. Possible interventions could include alcohol screening, treatment of women with alcohol dependence, self-help groups for women with alcohol dependence, lowered alcohol content, taxes and pricing, enforcement of on-premise policies and server training on interventions, and advertising bans/controls. A formal request that the industry enforce its own guidelines could go far to remove their modeling/suggestion for women to drink.

MADD's success in raising the visibility of the problem of drunk driving and changing enforcement policies is a model that can be used for FAS. Changing society's opinion of the problem is important, as underage drinkers also include women of childbearing age with potential exposures to a fetus as well as the woman herself. Raising awareness to gain society's support is important. Dr. Babor suggested that the Task Force reviewing the strategies in the proposed matrix, examining the advantages and disadvantages of each area and its relevance to prenatal alcohol exposure.

It was noted that educating people about the issues of FAS must continue. Even a woman who is a low-risk drinker needs to know that she needs to stop drinking when she becomes pregnant.

Business Items

Updates were provided by the agencies and organizations' representatives. The Task Force request that the **Surgeon General reissue the advisory about drinking in pregnancy** was forwarded again with the further information that was requested.

A report on the **Reauthorization of the IDEA** was given by Dr. Deborah Cohen. Prior to its passage, the Task Force, NOFAS and the Arc of the U.S. urged for inclusion of FAS in the list of conditions in the act, but the bill was already close to passing. It was recommended that the Task Force work with the Department of Education as the regulations for IDEA are developed. The inclusion of FAS in the IDEA was to be further discussed in the next day's Post-Exposure work group meeting.

Teacher FAS Certification efforts were outlined by Dr. Schadt. Dr. Schadt reported that teacher certification issues are not addressed at the national level; rather, they vary state by state. Black Hills State University was recently funded by CDC to develop a teacher education curriculum. He has met with a variety of individuals in the state and has gained their support in these efforts. If the pilot project is successful, Black Hills may offer a one-hour FAS course. He continues to meet with other state and national contacts raising awareness about the issue of FAS teacher certification. He will report back on his progress at the next Task Force meeting.

SAMHSA: Ms. Callie Gass and Dr. Deborah Stone provided an update on SAMHSA's FASD Center for Excellence activities. SAMHSA awarded contracts to state juvenile justice systems to integrate FASD practice into their systems of care. The first contracts were awarded before Thanksgiving and another ten states will be awarded in late December. These projects will test whether evidence-based practices can be integrated into these systems to produce better results for FASD, or to prevent an alcohol-exposed pregnancy, and to see if the system can absorb the change. The FASD Center for Excellence Steering Committee met recently and addressed many of the same issues that the Task Force is discussing today. FASD Center for Excellence training activities are ongoing. The Center held a Women's Summit with NOFAS. With the help of University of Washington and NOFAS, a subsequent video, *Recovering Hope*, was produced by and for mothers of babies with FASD. This video will be available soon from the National Clearinghouse.

ICCFAS: Dr. Sally Anderson reported on the ICCFAS' role to improve communication, cooperation, and collaboration among the disciplines and federal agencies that address health, disabilities, education, developmental disabilities, alcohol research and social services. The ICCFAS' work revolves around interventions for children and families affected by prenatal alcohol exposures, improving methods for diagnosis and face identification, increasing research in FAS etiology and pathogenesis, prevention of drinking during pregnancy, and increasing information dissemination. Their plans for the next few years were outlined, and included: fostering behavioral research, promoting education on FASD; enhanced work with juvenile justice to identify children damaged by ethanol exposure early; improving diagnosis and fostering research on FAS' etiology and pathogenesis; increasing community education and information dissemination; and translation of research to prevent drinking during pregnancy.

Interest in FASD has risen in other agencies (e.g., DOE and the OJJPD), as has Congressional interest. NIAAA has funded \$16-20 million to FASD research, mostly using animal models. NIAAA also continues to fund collaborative initiatives on FAS, now involving 4-5 other countries as well as the U.S., to assemble the knowledge and to explore how to transfer animal research to humans. NIAAA and NICHD also funded another international study on prenatal alcohol consumption, stillbirths and SIDS, to follow evidence that these are in a continuum that results in those conditions or FASD. This will be multi-disciplinary, multi-site collaborative research project.

AAP: Dr. Brenneman reported on findings from the CDC-AAP physicians' survey regarding alcohol consumption during pregnancy and FAS. Regarding knowledge, training, or expertise to care for children with FAS, 77% reported lacking the needed knowledge or training, and 29% lacked the time. While their knowledge of FAS' features and its epidemiology was good, they were less prepared to diagnose, manage, and care for a patient with FAS. A report will be published in *Pediatrics* in the next several months.

NOFAS: Ms. Mitchell reported that NOFAS now has four affiliates and plan to bring on four more. They will soon issue an advocacy guide and materials developed with CDC for use in Kindergarten-12th grade, and are continuing their work with the Cherokee Nation.

ACOG: Dr. Sokol reported that CDC and ACOG are working together to advance OB/GYNs' understanding of how to screen women for alcohol use and how to conduct brief interventions in order to prevent alcohol-exposed pregnancies. They are also in the process of obtaining ACOG endorsement of the recently published FAS Guidelines.

MOD: Ms. Antrobus, from the March of Dimes Georgia Chapter, reported on the MOD's campaign on prematurity. The campaign goal is to reduce preterm births to 10.1% by 2007 and to 7.6% by 2010. Data related to preterm birth, adverse outcomes, risk factors, and factors contributing to rising preterm birth rates were reported. MOD's prematurity campaign includes a focus on equity in health outcomes and healthcare. The campaign's goal is to "Prevent the Preventable" -- unintended pregnancy, inadequate folic acid levels, extremes of weight, tobacco/drug use, use of some prescription drugs, environmental toxins, known genetic/familial risks, etc., that result in PTB. With \$75 million to invest in the next five years, the MOD will aim outreach to those at risk, with signs/symptoms indicating the possibility of a PTB; to provide support to families with a PTB baby; and to increase awareness of PTB among the public.

CDC: Dr. Floyd reported that CDC has worked to establish state-based FAS surveillance systems and has monitored alcohol exposure rates among childbearing age women through the BRFSS. CDC has also tested approaches that intervene with women at risk for an alcohol-exposed pregnancy along with community-level prevention strategies, such as provider education and public awareness campaigns.

Dr. Floyd described the recently funded FAS Prevention projects. These projects have multiple components, including setting up FAS surveillance systems (using the FASSNET methodology as its framework), monitoring alcohol consumption, developing individual and community-level interventions for women at risk for an alcohol-exposed pregnancy, and linking children to services. Two new research projects were funded to explore the development and evaluation of self-guided change community-based approaches. The Project Choices preliminary analysis will be presented to NCBDDD in January 2005. Abstracts will be submitted for publication to disseminate the results. As

mentioned by Dr. Sokol, work will continue with ACOG on screening and brief interventions.

Mr. Richard Fenton, Deputy Director of **Centers for Medicare and Medicaid Services' (CMS)** Family and Children's Health Programs Group, presented an overview of the Medicaid program as it relates to women and children. State CMS' Medicaid programs are reviewed and approved by CMS, but the state programs determine services above minimum CMS requirements. CMS pays a 1:2 match, sometimes up to 65% of the state investment. Some states require special waivers to expand their coverage beyond the traditional Medicaid parameters and could cover the costs by running the programs through managed care.

Of the country's 44 million Medicaid beneficiaries, most (75%) are children and mothers. The other 25% are the disabled or elderly, who constitute most of the program's costs. Where 16% of state budgets were historically used to fund Medicaid, it now generally takes ~22-23%. Medicaid is growing and the states are trying to cover and/or reduce their services. The states' minimum eligibility requirements were described, in several categories: categorically needy, medically needy, EPSDT, and S-CHIP.

Discussion included:

- EPSDT is covered under S-CHIP if the state chooses to do so. If they do not, the children get coverage that is comparable to other health insurance programs and immunization services. The biggest expense involved in EPSDT is for treatment. State can include or expand the program, or go to a separate program; some do both. The EPSDT intake form has no specific question about prenatal exposure to alcohol.
- In family planning services for the categorically needy, any women covered by Medicaid can see a doctor to get contraception; and since all states adopted the pharmacy coverage, can they get contraception? Yes, they can. Family planning is paid at a higher federal match. There are waivers to cover postpartum costs for women (to help her not become pregnant again), some to 60 days; the child is eligible for one year whether or not the mother is.
- Are EPSDT medical or behavioral services covered when diagnosed by physician with an ICD-9 or -10 Code? The child receives services for medically necessary treatment, which is defined state by state.
- States are implementing managed care programs for Medicaid. Whether or not they specifically identify women (alcohol use) or children at risk (alcohol exposed) depends on the individual state programs. CMS allows the states to use their own clinical criteria and guidelines to provide services within broad specific service areas. This kind of flexibility both hurts and helps. With the states' need to save money, if something can demonstrate savings, it will be done and other states will follow. If identifying a child as prenatally exposed to alcohol, or if using contraception to reduce alcohol-exposed pregnancies were shown to result in a cost saving to the program, these strategies would be accepted.

- A new CMS Division is being created set up to share the states' best practices and quality issues. Those guidelines are expected to be adapted if they show savings, especially if coupled with demonstrated quality.
- Historically, screening for EPSDT has been poorly reimbursed; the funding goes to sick visits, and all the states are at a loss as to how to balance their budgets. Decreasing the reimbursement for the office visit essentially decreases access (which is hard to define and measure) since pediatricians cannot afford to make up the difference. The only, and very small, "stick" available is for CMS to not pay for services unless they are increased, but that does not help anyone much.
- There is also a problem with coverage for adults with FASD, and Medicaid's lack of coverage (e.g., in Maryland) for adult dental services. Few providers want to see a Medicaid patient and the waiting lists are long. Under the fee for service system, physicians were more willing to provide health care, but now the "medical home" concept is encouraged. For children, many physicians do not offer EPSDT services because they perceive little difference in the services the child will receive and because of the time needed to complete the forms. The real difference has occurred in specialty care (e.g., physical or occupational therapy), where professionals able to file for Medicaid reimbursement are hard to find. Dr. Wright suggested checking what recommendations by the AAP and ACOG address EPSDT.
- At question is how the Task Force should approach state Medicaid offices to ask about standards of care. For example, the New Jersey FASD Task Force asked Medicaid to add prenatal screening as a standard for prenatal care and preconceptional health screening, a minimal cost to implement.
- Any studies demonstrating costs savings would be considered (e.g., future savings from providing juvenile mental health care estimated by the NIMH and Justice). Dr. Wright suggested giving the states the best practices to incorporate those into their Medicaid planning, to improve programs and lower costs.

A **presentation on person-first terminology** was provided by Ms. Melinda M. Ohlemiller. This methodology uses the person first and then the descriptor (e.g. children/boy/girl with FASD). While this can be cumbersome at first, it eventually flows naturally in conversation. Families do notice when person-first language is used and that is an instant rapport-builder. Person-first terminology is simply good common sense.

Workgroup Reports were provided. Dr. Cohen reported on the **Post-Exposure Workgroup**. The workgroup will draft a Task Force letter about including FAS in the IDEA regulations. The letter should be circulated to Task Force before being sent to the Secretary of the Department of Education. An update on workgroup activities related to the inclusion of FAS in the DSM5 was also provided. The workgroup recommended that consultants be engaged to advise the Task Force on research methodologies useful to setting a research agenda, on the first full day of the next Task Force meeting, and that Task Force business be conducted on the second day.

Dr. Miller reported for the ***Prevention Workgroup***, which discussed Dr. Caetano's report and Dr. Babor's matrix. The group also brainstormed on key principles to consider in determining which strategies would be most relevant and effective in FAS prevention. A follow-up conference call or meeting of the Prevention Workgroup will be held prior to the next Task Force meeting. June 2005 is the target date for completion of the workgroup's preliminary report.

Workgroups may also have in-person meetings in between the formal Task Force meetings if necessary.

Public comment was solicited, to no response. Date options for the *next meeting* will be circulated to the members by CDC.

**Centers for Disease Control and Prevention
National Center for Birth Defects and Developmental Disorders
National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect**

**Minutes of the Meeting
December 6-7, 2004**

December 6, 2004

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was convened on December 6-7, 2004, in Atlanta, GA, by the Centers for Disease Control and Prevention's (CDC) National Center for Birth Defects and Developmental Disabilities (NCBDDD). The meeting was convened at 9:00 a.m. by Chair, Dr. Jean A. Wright.

Opening Comments

Dr. Wright welcomed the attendees and expressed her pleasure at being present. She was unable to attend the previous meeting because she had scheduled a trip to China to adopt her daughter. Dr. Calhoun introduced Dr. Sally Anderson, the new Executive Secretary of the Interagency Coordinating Committee for Fetal Alcohol Syndrome (ICCFAS).

Designated Federal Official (DFO) Dr. Louise Floyd indicated that the work of this Task Force over the past two years has mainly focused on FAS diagnostics and referral. While work in this area and in the area of services for children affected by FASD will continue, it is now important to focus time and efforts on prevention. Dr. Floyd reviewed the meeting agenda for the day indicating that time will be spent orienting Task Force members, particularly newly appointed members, to the epidemiology of women and alcohol, what prevention strategies work, and the challenges of moving prevention research into practice. A special session on alcohol advertising and adolescent girls will also be presented. This information is provided to help the Task Force begin to develop an FASD prevention agenda.

Dr. Floyd also announced that this is her last meeting acting as DFO. Mary Kate Weber, from the CDC FAS Prevention Team, will be named DFO following this meeting.

Task Force Members, Liaisons, and Attendees

Acting Executive Secretary:	Coleen Boyle, PhD, Division on Birth Defects & Developmental Disabilities (DBDDD), NCBDDD, CDC
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Standing Member:	Faye J. Calhoun, DPA, MS, National Institute for Alcohol Abuse and Alcoholism, National Institutes of Health

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Liaison Representatives present:

American Academy of Pediatrics: George Brennen, MD, FAAP, Committee on
Native American Child Health, Elkridge, MO
American College of Obstetrics and Gynecology: Robert J. Sokol, MD, Department of
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Development, School of Medicine, Wayne State University, Detroit, MI
March of Dimes: Elise Linden Antrobus (Atlanta, GA) for Karla Damus
National Organization on Fetal Alcohol Syndrome: Kathleen T. Mitchell, Washington,
D.C.
The Arc: Sharon Davis, PhD, Professional and Family Services, Silver Springs, MD
Center for Science in the Public Interest: George A. Hacker, JD, Alcohol Policy
Project, Washington, D.C.

Guest Speakers:

Thomas Babor, MD, MPH, Department of Community Medicine and Healthcare,
University of Connecticut Health Center
David Jernigan, PhD, Center on Alcohol Marketing and Youth at Georgetown,
Washington, D.C.
Richard Fenton, Family Children's Health Programs, Centers for Medicare and Medicaid
Services, Baltimore, MD

Other Attendees:

Sally Anderson, PhD, National Institute for Alcohol Abuse and Alcoholism, National
Institutes of Health, Bethesda, MD
Jacquelyn Bertrand, PhD, FAS Prevention Team, DBDDD, NCBDDD, CDC
Robert D. Brewer, MD, MPH, Emerging Investigations and Analytic Methods Branch
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Sherry D. Ceperich, PhD, FAS Prevention Team, DBDDD, NCBDDD, CDC
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Callie Gass, FAS Center for Excellence, Center for Substance Abuse Prevention (CSAP), Substance Abuse and Mental Health Services Administration (SAMHSA)
Christine Hammond, Office of Developmental Disabilities (DD), Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD), Georgia Department of Human Resources (GA DHR)
Jacqueline Miller, MD, EIAMB, DACH, NCCDPHP, CDC
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Ruth Shults, PhD, Motor Vehicle Injury Prevention Team (MVIPT), Division of Unintentional Injury Prevention (DUIP), National Center for Injury Prevention and Control (NCIPC), CDC
Mandy Stahre, MPH, ASPH Fellow, DACH, NCCDPHP, CDC
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Mary Kate Weber, MPH, FAS Prevention Team, DBDDD, NCBDDD, CDC
Jacqueline Vowell, Committee Management Specialist, Fetal Alcohol Prevention Team, DBDDD, NCBDDD, CDC

Women and Alcohol: What Do the Data Tell Us?

Dr. Raul Caetano outlined the main objectives of his presentation: (1) to provide census-based and epidemiological information on women of childbearing age, births, and pregnancies in the U.S.; (2) to describe the epidemiological data (using the National Epidemiological Survey on Alcohol-Related Conditions – NESARC) on alcohol consumption among pregnant and non-pregnant women; and (3) to briefly discuss approaches to prevention. Dr. Caetano focused more on (1) and (2) since Dr. Babor will be describing prevention strategies in more depth during his presentation. The data discussed here were presented as a paper at the July 2004 CDC NCBDDD conference.

Birth and Pregnancy

- Based on 2002 data, Hispanic women have the highest fertility rate (80 live births per 1,000 women) versus the national average of 61 per 1,000.
- The U.S. has a stable rate of approximately 4 million births a year, many occurring among unmarried women.
- Almost 50% of the pregnancies are unintended and 50% occur among women in minority populations.
- Unintended pregnancy is more common among younger and unmarried women, black women, those without a high school education, and/or those on Medicaid. Among white women, unintended pregnancies are associated with binge drinking.

Alcohol Use

- CDC's Behavioral Risk Factor Surveillance Survey (BRFSS) data indicate that the rates of frequent (≥7 drinks/week) and binge drinking (≥5 drinks/occasion) among pregnant women ranged from 2-4% from 1991 to 1999. Rates of frequent drinking and binge drinking for non-pregnant women ranged from 10-13% during this time period.

- The NESARC is a longitudinal survey of non-institutionalized people 18 years and older. This NIAAA survey provides estimates for the nation as a whole on topics related to alcohol and drug use, abuse and dependence and their associated disabilities. The NESARC survey involves in-person interviews in a multistage random sample. Random households were selected in different areas. They also sampled people living in institutions (dormitories, boarding houses, shelters, etc.). There was no oversampling of American Indians, whose ~2% overall proportion to the U.S. population was matched by the study (this small sample number does not support analysis by ethnicity.) Oversampling was done, however, for blacks and Hispanics. The same methods were used everywhere, except perhaps slightly differently in sparsely populated areas such as Alaska.
- The NESARC asked women two questions about pregnancy: (1) Are you pregnant now?" and "Were you pregnant at any point in the last 12 months?" All the women who were pregnant at the time of interview also stated that they were pregnant at some point "in the last 12 months." Thus, Dr. Caetano's analysis includes 1,517 pregnant women and 10,576 non-pregnant women. Some of the findings from this analysis are as follows:
 - Approximately 40% of non-pregnant women and about 38% of pregnant women reported drinking alcohol. Binge drinking rates for both groups were right below 20%.
 - Among non-pregnant women drinkers: ~28% were 18-20 years (underage); ~40% were 21-29 years; ~44% were 30-39; ~46% were 40-44. Among pregnant women drinkers: ~30% were 18-20 years (underage); ~37% were 21-29 years; ~44% were 30-39; ~28% were 40-44.
 - For non-pregnant women, ~20% had 4 drinks on one occasion, and ~7% were alcohol-dependent. For pregnant women, ~16% had 4 drinks on one occasion, and ~4% were alcohol-dependent.
 - By ethnicity: White women are more at risk of frequent drinking and are at higher risk than blacks and Hispanics. Those of mixed race are also at risk. Although the data are in the early stages of collection, the highest risk for frequent or binge drinking and abuse/dependency appears to be among Native Hawaiians and Pacific Islanders, followed by Native Alaskans.
 - In order to predict heavy drinking (defined as drinking four or more drinks, alcohol abuse, alcohol dependence) among pregnant and non-pregnant women using the NESARC data, Dr. Caetano conducted a multivariate logistic regression. Pregnant women who were 21-29 years of age were more likely to be heavy drinkers. Those who were single or never married were 2 to 4 times more likely to be heavy drinkers. The risk of heavy drinking rises with income. Blacks, Hispanics and Asians were all at less risk than white women.
 - In the data for non-pregnant women, SES indicators play a significant role. and, as with pregnant women, race/ethnicity seemed to offer a protective factor. White women are at greater risk of being a heavy drinkers compared to Black, Hispanic, and Asian women.

The steps to prevention are 1) Surveillance (what is the size of problem?); 2) Risk Factor Identification (what are the risks? alcohol); 3) Intervention Evaluation (what works and for what groups); and 4) Implementation (how to do it?).

Levels of prevention when alcohol is a risk factor include the following:

1. Universal: Directed at all members of a population (e.g., all women, all pregnant women) to reduce alcohol consumption in the general population, support abstinence during pregnancy, and to raise FAS risk awareness in routine health care.
2. Selective: Directed at subgroups of individuals with a risk higher than average (e.g., drinkers, pregnant women who drink, their partners) to screen and identify at risk individuals providing appropriate interventions (e.g., brief interventions).
3. Indicated: Directed at the groups who are at highest risk (e.g., high risk drinkers, abusers and dependent) to deliver more intense interventions (e.g., treatment).

Different levels of intervention call for different types of intervention. Dr. Caetano used the IOM's funnel diagram (Attachment #1) to describe the use of the above interventions, showing the types of drinkers (abstainer, low risk, drinkers who drink 4+, abusers, dependent) at each stage of the funnel and the prevention strategies relevant at each stage. The model moves from universal interventions (reduce availability), to selective interventions (screening, counseling, brief intervention), to indicated interventions (intervention, treatment). The data used to chart this framework are based on census data, data from research surveys by the NIAAA (1991-92 national epidemiologic data), and NESARC (2002).

Dr. Caetano proposed that most of the population follows a gradual progression from abstainer to high risk, begging the question of where to intervene. In Dr. Caetano's opinion, the only way to proceed is to begin with universal interventions across the continuum from abstinence to initial drinking and then onward. The interventions would begin with reduced availability of alcohol, with all other interventions coming later.

Primary (universal) interventions would be based on the "public health approach", which proposes that the higher the average amount of alcohol consumed, the greater the prevalence of problems. Prevention interventions are directed at the reduction of average alcohol consumption by limiting the availability of alcohol. Education and persuasion interventions fulfill a public service, provide a perspective on the problem, promote debate and discussion, offer a rationale for alcohol policies, serve a supportive function to change, and influence the focus of policy work.

Overall, Dr. Caetano offered this as a pragmatic approach. With women at all levels of risk, the approach must be comprehensive, combining all levels of interventions. Using only universal interventions could stop the flow of women from low risk to high risk drinking, but to be more effective, they should not address only FAS or only women. They should be part of a wider strategy to reduce all problems.

The strong research base presents good opportunities to enable rationale choices, to combine rationally-selected strategies into an integrated overall policy, to implement

policies at multiple levels, and to strengthen public awareness and support.

Discussion included:

- Dr. Berner indicated that there is another group at high risk, sometimes from the time they are toddlers. These individuals, particularly girls, are offered alcohol at an early age to reduce their resistance to sexual abuse. Since alcohol availability to an abuser is essentially unlimited, an intervention is needed to address those with early abuse. Dr. Caetano hoped that the reduction of availability would help in that regard, but that would not be the only intervention needed.
- Dr. Sokol commented that whether or not younger women drink more than white women does not impact the highest risk populations (although that is not true for binge drinking), as FAS is not generally a problem of young drinkers. Noting that there were still alcoholics during Prohibition, he also expects that limiting availability would be challenged and unlikely to succeed, since “drinkers will drink,” regardless. However, Mr. Hacker reported data on alcohol bans’ ability to dramatically lower drinking rates, mostly among underage drinkers. They can also lower the incidence of negative effects, such as motor vehicle injuries.

What Works? An Overview of Effective Prevention Strategies to Reduce the Risk of Problem Drinking and Alcohol-Exposed Pregnancies

Dr. Thomas Babor, from the University of Connecticut, presented findings from the report, *Alcohol: No Ordinary Commodity* (Harvard University Press).

The Alcohol Public Policy Group (APPG), which included Dr. Babor and 14 other authors, reviewed the world literature on strategies and interventions related to alcohol use. The report, sponsored by the World Health Organization and the Society for the Study of Addiction, updates and expands the previous work, *Alcohol Policy and the Public Good* (Edwards, et al., 1994). *Alcohol, No Ordinary Commodity* outlines the new developments in epidemiological research, including alcohol’s role in the global burden of disease, the growth of the knowledge base on policy-related strategies and interventions, and new understandings of the policymaking process at the local, national and international levels. The title was arrived at when the authors’ concluded that alcohol has a conflicted role in society. While alcohol is viewed as an important commodity, offering economic growth, employment, and tax revenues, it also causes harm. Alcohol’s benefits come at an enormous cost to society. Alcohol has the ability to cause medical, psychological and social harms. These effects play out through physical toxicity, intoxication, and dependence. There are no simple interventions to its abuse; it involves a complex relationship with individuals who drink.

The APPG’s review focused on the evidence for 31 policy-relevant prevention strategies and interventions. These were subclassified into seven categories: regulating alcohol’s physical availability, pricing and taxation; modifying the drinking context, education and persuasion, regulation of alcohol promotion, drinking-driving countermeasures, and treatment and early intervention.

Dr. Babor reviewed the chapter that rated the 31 policy-relevant prevention strategies

and interventions from zero (no evidence) to three pluses. Each strategy was assessed on the following criteria: (1) evidence of effectiveness (quality of scientific information); (2) breadth of research support (quantity/consistency of the evidence); (3) tested across cultures, and (4) cost to implement and sustain.

The APPG's evaluation standards also included (1) consideration of the target groups (the general population of drinkers and nondrinkers, the high risk drinkers or vulnerable groups, and those with harmful drinking and alcohol dependence); (2) adverse side effects (tax evasion, criminal activity, illicit production); (3) population reach (number of people affected by the intervention), and (4) feasibility (in terms of political and economic implications, as well as side effects).

- *Taxation* was the first aspect explored. This strategy produced the highest ratings across the board. There is very good evidence that the higher the tax, the less the alcohol consumption. People increase drinking when prices are lowered and decrease when prices rise. Heavy or problem drinkers are no exception to this rule. Economic studies demonstrate that increased alcohol beverage taxes and prices relate to reductions in alcohol-related problems. And, since they can both generate direct revenue and reduce alcohol-related harm, alcohol taxes are an attractive public policy tool. The most important downside to raising alcohol taxes is smuggling and illegal in-country alcohol production.
- *Regulating alcohol's physical availability* (convenience of obtaining and consuming alcohol) was explored. This option, which offers several interventions, also is supported positively in the literature evidence as indicated below:
 - Total ban on sales/prohibition: The evidence demonstrates that this is very effective, especially when supported by religious or cultural traditions. But it involves a high cost for enforcement, and secondary challenges such as smuggling and the cost of prosecution.
 - Minimum legal purchase age: Raising the drinking age costs little and reduces consumption in a group of concern, underage drinkers. Regulations directed at commercial vendors who sell to minors and ignore other restrictions can be effective if the system can suspend or revoke a license.
 - Government monopoly of retail sales (i.e., off-premise monopoly systems) can limit alcohol consumption and alcohol-related problems.
 - Limiting hours/days of sales: Reductions in the hours and days of sale, numbers of alcohol outlets, and restricted alcohol access are associated with reductions in both alcohol use and alcohol-related problems.
 - Extreme restrictions (e.g., total prohibition) can lower drinking and reduce alcohol problems, but frequent adverse side effects include the criminality associated with illicit markets.
 - Different availability of alcohol strength: Promoting low alcohol content beverages has the potential to reduce the level of absolute alcohol consumed and associated intoxication and impairment.

- *Modifying the drinking context*

These types of strategies are somewhat effective. Interventions include:

- Policies to not serve intoxicated patrons
 - Training of bar staff/managers to prevent and better manage aggression
 - Voluntary codes of bar practice: this does not seem to change patrons' drinking patterns, because it requires enforcement.
 - Enforcing serving regulations and increasing the legal liability of bar staff and owners for the actions of those they serve are the most effective options. An example of this is Responsible Beverage Service (RBS) programs. These programs focus on attitudes, knowledge, skills, and practices of those who serve alcohol beverages on licensed premises. If supported by actual changes in the serving policies of licensed establishments and reinforced by local police, RBS training can reduce heavy consumption and high risk drinking.
- *Community mobilization:* There is evidence that this has an effect on population rates in targeted groups, such as young women of childbearing age. Community mobilization raises public awareness of problems associated with on-premise drinking in licensed establishments and can result in specific solutions to problems. Community pressure can force bar owners' recognition of their responsibility to the community (e.g., noise level, patron behavior such as aggression). It is important to note, however, that the long-term sustainability of these kinds of efforts remains to be demonstrated.
 - *Drinking and driving countermeasures* are the success stories in the population and public health prevention literature. All interventions (e.g., sobriety checkpoints, random breath testing, lowered BAC limits, etc.) are important in sending the message to the population that it is unacceptable to drink and drive. In the mid-1990s, these efforts resulted in a big shift among older adults to drink beverages of lower alcohol content. The literature indicates that drinking and driving countermeasures consistently produced long-term problem reductions between 5% and 30%. The initiatives of Mothers Against Drunk Driving (MADD) cannot be underestimated in their impact on policies and on changing the attitudes of the broader society. While the research does not demonstrate a causal relationship, the data indicate that the best interventions are to certain sub-populations. It was not the severity of punishment or the type of intervention, but how the strategy was implemented and enforced, that had impact. The more prominent the enforcement and the more it is perceived as likely, the more it intervenes in drinking. Deterrence-based approaches, using strategies such as random breath testing, yield few arrests but offer substantial accident reductions. Also, the persistent delinquency of some impaired drivers should not take away from the enormous success of recent years.
 - *Limiting access to driving by young people.* Adolescents aged 16-20 years are at higher risk for alcohol-involved crashes as a result of their limited driving experience and their tendency to experiment with heavy or binge drinking. Traditional countermeasures such as driver training and school-based education programs are either ineffective or have yielded mixed results. One effective measure is the use of graduated licensing for

- novice drivers, which limits the time and other conditions of driving during the first few years of licensing.
 - *Treatment programs as an alternative to punishment.* Evidence from some countries supports the effectiveness of treatment plus license suspension in reducing repeat offenses of drunk driving. Successful programs are well structured, go beyond information provision to address the alcohol abuse, are conducted for more than 10 weeks, and have rules of attendance enforced by a court.
- *Education and persuasion* (e.g., alcohol education in schools and colleges, public service messages, warning labels). The data do not support the ability of any of these interventions to substantially reduce heavy drinking or population rates of alcohol consumption. This position was controversial, as studies do show modest effects on knowledge and attitudes, but those tend to fade. Their cost is high for only a marginal effect on the population at risk. While Dr. Babor does not abandon alcohol education, he might focus it so that young women would know to not drink if they are pregnant. If educational approaches are to be used, they should be implemented within the framework of broader environmental interventions. Public Service Announcements (PSAs) were also shown to be ineffective in changing behavior. These messages also have to compete with the high-quality pro-drinking messages that appear frequently in the mass media.
 - *Counter-advertising* involves sharing information about a product, its effects, and the industry that promotes it, in order to decrease its appeal and use. An example of this is a health warning label, such as the one currently on alcoholic beverages. Although a significant proportion of the population reports seeing these warning labels, research indicates that exposure produces no change in drinking behavior per se.
- *Regulating alcohol promotion.* There is limited evidence that advertising bans work, and insufficient evidence on the effectiveness of controlling advertising content. However, this has been a well-established precaution used by governments throughout the world, despite opposition from the alcoholic beverage industry. Findings suggest that while the restrictions have not achieved a major reduction in drinking and related harms in the short-term, countries with greater restrictions on advertising have less drinking and fewer alcohol-related problems (Saffer, 1991). In the U.S., this is hard to research, especially as it relates to the effects on particular sub-groups. The general theory is that people learn to drink from the behavior modeled among their peers. Bans, content controls and restricting exposure have not reached the intended goals, partly because the industry in the U.S. was entrusted with being its own watchdog and is not effective in its own self-regulation.
- *Treatment and early intervention:* In general, exposure to any treatment is associated with significant reductions in alcohol use and related problems, regardless of the type of intervention used. Regarding specific treatment modalities, the weight of evidence suggests that behavioral treatments are likely to be more effective than insight-oriented therapies. Treatment of alcohol problems is effective and has research support, but it involves high costs and shows no significant effect

on the truly addicted drinker.

- *Brief interventions:* These consist of one to three sessions of counseling or advice delivered in general medical settings. Randomized controlled trials (conducted in a variety of settings) indicate that clinically significant changes in drinking behavior and related problems can follow from brief interventions with non-alcoholic heavy drinkers. This is achievable at a moderate cost when targeted to such high-risk groups as pregnant women or women of childbearing age.

Dr. Babor proposed the following strategies as best practices.

- Minimum legal age purchase regulations
- Government monopoly of retail sales
- Restricted hours or days of sales
- Outlet density restriction
- Alcohol taxes
- Sobriety check points
- Lowered BAC limits
- Administrative license suspension
- Graduated licensing for novice driver
- Brief interventions for hazardous drinkers

Less effective (“worst”) practices listed were not to imply that some things, such as warning labels are not good or should be abandoned. However, Dr. Babor indicated that he would not substitute these for the strategies considered Best Practices. The least effective practices, based on review of the literature, include:

- Voluntary codes of bar practice
- Promoting alcohol-free activities
- Alcohol education in schools
- College student education
- Public service messages
- Warning labels
- Designated drivers and ride services

Cost Effectiveness. The cost-effectiveness of different policy options were outlined, as studied and modeled by the WHO (published in 2004). They delineated the number of years of functional life lost due to different disease conditions and the effects on health in terms of Disability Adjusted Life Years (DALYs). They reviewed the data supporting physician advice, taxes, random breath testing, advertising bans, and reduced alcohol access. Using DALYs as a function of different interventions, the European data report suggested that general practitioners’ advice in primary healthcare settings was second only to random breath testing as a strategy of low cost and impact on the target population (*note: statement made in error – see page 30 for correction*).

Analysis of DALYs’ overall impact compared interventions to suggest which would invite the investment of political capital. The factors needed for such decisions included:

- Better epidemiologic understanding of the population at risk.
- Better definition of alcohol-related pregnancy risk.

- More specific information about the effects of prevention policies on the population at risk.

Nayak and Kaskutas' (2004) study of a national sample of women aged 18-39 years found that 4.8% were pregnant, 33.9% expected to be pregnant in the next 5 years, and 61.3% thought it unlikely that they would be pregnant in the next 5 years. In addition, CDC data indicate that 16.2% of pregnant women and 30.3% of those likely to become pregnant engage in risky drinking (\$7 drinks per week, \$5 drinks per occasion per year). Actions to take, as suggested by the current knowledge, include support of general population strategies due to their cost-effectiveness and synergistic effects, and support of effective harm reduction and high risk group strategies. Such strategies include screening and brief intervention of all women of childbearing age, server interventions, enforcement of minimum purchase age, ad bans, and ad content/exposure restrictions.

Dr. Babor felt that there is cause for optimism with regard to policy changes. There are now more effective, evidence-based alcohol policies than ever to better serve the public good. Alcohol policies that limit access to alcoholic beverages, increase the price of alcohol, and enforce laws and regulations through deterrence, are likely to reduce the harm linked to specific drinking patterns and per capita consumption. Alcohol problems can be minimized or prevented using a coordinated, systematic policy response.

Public policies have a major impact on the resources allocated for treatment and the preventive measures available to people within a country or region, but such alcohol policies are seldom informed by scientific evidence or public health considerations. Some popular policy options (e.g., school-based alcohol education) have relatively small or no effects at all on population rates of alcohol-related morbidity and mortality, while many unpopular policy options such as higher taxes have significant effects.

Conclusions: Because alcohol is no ordinary commodity, the public has a right to expect a more enlightened, evidence-based approach to related policy. Knowledge needs to be amassed about what works or does not work, and that needs to be provided to policy makers to produce the synergistic effects of policy married to science.

Alcohol Advertising and Adolescent Girls

Dr. David Jernigan, from the Center on Alcohol Marketing and Youth (CAMY), Georgetown University, presented on the Center's findings on alcohol advertising and adolescent girls.

Regarding underage drinking, data from CDC's Youth Risk Behavior Survey (YRBS) indicate little progress over the last 12 years, despite enormous efforts in last few years to reduce the problem. Some reductions have been seen among boys in the last 10 years, but not among girls. The market has produced a "natural experiment" in the form of new products such as "alcopops," "malternatives," hard lemonade, and Bacardi Light, but these are not being evaluated. The bright coloring of their presentation helps the industry introduce them to initiating drinkers, with the probable desired effect primarily directed to girls.

The NIDA survey, Monitoring the Future (MTF), revealed that 8th and 10th grade girls surpassed boys for the first time in 2002 as “current drinkers” (i.e., having had a drink in the past 30 days). CDC’s 2003 YRBS data show 9th grade girls drinking more alcohol than 9th grade boys in the past month (38.5% versus 33.9%) as well as more binge drinking (5 drinks on one or more occasion in the past month) than boys, 20.9% and 18.8%, respectively.

The consequences of youth drinking are serious. According to the CDC, alcohol plays a substantial role in the three leading causes of death among young people: unintentional injuries (includes motor vehicle accidents), suicide and homicide. A poll of over 11,000 students from 128 colleges found that college students who got drunk for the first time before age 13 were twice as likely to say they had unplanned sex because of drinking compared to those who waited to drink until they were 19 or older. This group was also more likely to say they had unprotected sex because of drinking as well. Teen girls who drink are up to 63% more likely to become teen mothers (Dee, 2001).

CAMY was interested in learned what parents’ perceptions of youth drinking were so they asked parents the same questions asked of youth in the Monitoring the Future survey. Parent awareness of youth drinking was low. Perception gaps range from 10-30%. For example, 60% of 15-16 year olds report they have consumed an alcoholic beverage while only 31% of their parents said that their child consumed an alcoholic beverage.

In addition to this, the underage youth market is substantial (accounting for 12-20% of the U.S. alcohol market) and is dominated by heavy drinking. Public health research has shown the youth exposure to alcohol advertising increases awareness of the advertising, which in turn influences young people’s beliefs about drinking, intentions to drink and drinking behavior (Grube, 1995; Collins, et al, 2003, Martin, et al, 2002). While many factors influence a young person’s drinking decisions, such as parents, peers, and the media, there is also reason to believe that advertising plays a role.

CAMY’s study reported \$590.4 million spent by the beer and alcohol industry on 6239 alcohol advertisements in magazines (2001-2002). Alcohol industry self-regulation is the principle means for regulating alcohol advertising in the U.S. Beer and distilled spirits are the most active marketers. Expenditures for 2002 were: Beer, ale - \$1.4 billion; Distilled Spirits – \$378 million; Wine - \$144 million.

The government recommended that the alcohol industry set up a self-policing code of conduct, but it is not enforced. The Beer Institute and the Distilled Spirits Council of the United States (DISCUS) have their own codes. Dr. Jernigan shared several excerpts from the Beer Institute code followed by actual advertisements that blatantly refuted what the code outlines. Some examples of the code are: “...materials should not portray sexual passion, promiscuity, or any other amorous activity as a result of consuming beer,” and “...materials should contain no claims or representations that individuals cannot obtain social, professional, educational, athletic, or financial success or status without beer consumption.” Dr. Jernigan also shared excerpts of the DISCUS

code with accompanying advertisements. This code is also not enforced. The DISCUS Code's preamble includes a pledge by the advertising community member to observe the Code's spirit as well as its letter, and to commit to the responsible placement and content of their brand communications.

CAMY was set up to monitor marketing practices of the alcohol industry and to focus attention and action on industry practices that jeopardize the health and safety of young people. CAMY is supported by grants from the Pew Charitable Trusts and the Robert Wood Johnson Foundation. Its project methodology uses the same data that is used by industry itself to assess exposure.

When compared to adults 21 and older, youth 12-20 saw per capita (1) 45% more beer ads and 12% more distilled spirit ads, (2) 65% more ads for alcopops and malternatives (e.g., Smirnoff Ice), and (3) 69% less wine ads. While the 21-34 year-old age group is heavily targeted in the beer and distilled spirits ads, CAMY found that the advertising was spilling over to younger, rather than older age groups. The picture for the wine industry is different. Data analysis revealed that the fewer number of wine ads suggest that the target populations can be reached without targeting youth directly. Except for Una DiLuna wine, most wine industry advertising is geared to those aged 35 years.

In a 2002 article in the *Archives of Pediatric and Adolescent Medicine*, researchers found that girls are much more overexposed to alcohol advertising than boys. When compared to women, girls saw 68% more beer advertising and 95% more malternatives advertising. When compared to young women (aged 21-34), girls saw more malternatives and beer advertising. Boys saw more advertisements than adult men but not more than young adult men. The rates of overexposure were lower.

In 2003, 298,054 alcohol product commercials appeared on television. According to CAMY, underage youth aged 12-20 were more likely than legal-age adults to have seen 69,054 of them (23%). CAMY also discovered that in 2003, alcohol ads appeared on 15 out of 15 television shows with the largest teen audiences. Dr. Jernigan presented data on television advertisement specific to the Atlanta Market in 2003. Youth overexposure occurred in over 600 programs. Three networks, Comedy Central, BET, and VH-1, routinely overexposed youth to alcohol advertisements.

Radio is very popular among teens. CAMY sampled 67,000 airings of radio ads for 25 leading alcohol brands in 104 markets in the summer of 2004. Preliminary 2004 CAMY data on youth exposure to radio advertisements show that, while boys in general had more exposure to alcohol advertising on the radio, girls had heavier exposure compared to women than the boys did as compared to men. In at least half of the markets, 19 brands more effectively exposed girls than legal age women, 8 brands did so for boys more effectively than legal age men; and 4 more effectively exposed girls than young adult women and only 3 brands more effectively exposed boys than young adult men.

A comparison was then done between exposures to minority youth versus those to all other youths (all rates are posted on the Center Website, www.camy.org). In 2002, compared to other youth, Hispanic youth age 12-20 were exposed to 24% more distilled

spirits and beer advertising, and 32% more ads for malternatives and alcopops in English language magazines. African American youth were exposed to 12% more beer ads and 56% more ads for distilled spirits on the radio. Alcohol advertisements were placed on 12 of the 15 programs most popular with Hispanic youth. Alcohol advertisements were placed on all 15 of those programs most popular with African American youth.

The alcohol industry cites its own “responsibility advertising,” saying that “...no one can match the alcohol industry’s long-term commitment to public-service advertising that discourages underage drinking...” (Jeff Perlman, American Advertising Federation). Youth are consistently far more likely to see a product ad than an alcohol industry ad about underage drinking. In 2002, adults were twice as likely as youth to see an alcohol product ad than one about underage drinking.

Dr. Jernigan concluded that:

- Intentional or not, the current beer and distilled spirits industry practices pervasively overexpose youth to alcohol advertising.
- The actions of the wine industry show that these kinds of practices are not necessary in order to advertise a product.
- This presentation only covered measured media. Other key areas include product placement, sponsorships, Spring Break, campus and sports marketing, and point of purchase.

The Center has tried to promote a national debate about underage drinking in general and about advertising exposure to youth in particular. They were successful in getting that message into the media. They continue to work toward achieving some reform in alcohol advertising. In the fall of 2003, the IOM report “*Underage Drinking, a Collective Responsibility*), suggested that:

1. The alcohol industry should move toward a 15% maximum youth audience composition for its advertising.
2. DHHS should monitor underage exposure to alcohol advertising on a continuing basis and fold those findings into an annual report to Congress on underage drinking.
3. DHHS should collect brand data through underage drinking surveys. The MTF survey was the vehicle that identified the impact the tobacco industry was making among youth, and there is no comparable question on alcohol.
4. There should be a national media campaign developed about underage drinking focused to adults, who do not have an accurate understanding of this problem.

Lowering the youth audience threshold was supported in 1999 by the FTC, which urged the industry to lower their reach from 50% to 30%. Four years later to the day, the FTC released a follow-up to the 1999 report to Congress and the Beer Institute announced that they would lower their threshold to 30%. The American Medical Association called for a 15% youth composition for alcohol ad placements, and no ads before 10 p.m.

MADD called for a 10% maximum exposure of youth audiences to alcohol advertising on television.

Reform initiatives. The efforts of bipartisan Congressional staffs to apply the IOM recommendations resulted in the STOP (Sober Truth On Preventing) Underage Drinking Act. It mandates an annual report on underage drinking, including youth exposure to alcohol advertising and information on youth alcohol brand preferences, as well as a small related pilot media campaign targeted to adults.

Legal research is underway to develop a policy agenda and to defend against First Amendment critiques. Class action suits have been filed in North Carolina, Ohio, Colorado, California and Washington, DC. Another 17 states are likely to join them in the next 6 months. The National Association of Attorneys General set up workgroups on underage drinking which are also examining youth exposure to advertising and the effect of alcohol enforcement strategies. The first underage drinking workgroup of 11 Attorneys General was soon followed by the Central and Western Attorneys General Workgroup (28 attorneys general) which will focus particularly on Hispanic and Native American youth.

Alcohol advertising reform at the state and local level were outlined:

- Ban alcohol advertising on public property
 - Philadelphia banned advertising in bus shelters since 27,000 youth ride buses, and many use city subsidies to ride.
 - Some sports, concerts, and other arts facilities (scoreboards, etc.) have dropped alcohol advertising (e.g., the University of Connecticut).
 - Public and post-secondary schools
 - Parks and recreational centers
 - Public publications (maps and tourist materials, magazines, etc.)
- The states can put industries' voluntary restrictions into law to make them enforceable without specific legislation to do so (e.g., as done in Ohio, by mandating no advertising within 500 yards of schools, etc.).
- Cities can restrict local retail signage or alcohol company sponsorships of family events such as July 4th events held on public property.

Funding and data licenses for CAMY are due to end in December 2004. Its funding was extended to complete its work. Analysis of the 2004 data will be completed this month, but the reports will continue until June 2005. Reports regarding alcohol advertisements on television (2001-2004), magazines (2001-2004), and radio (summer 2003, 2004) will be forthcoming. Dr. Jernigan is hopeful that CAMY's efforts in monitoring the alcohol industry will be picked up, as the industry's self-regulation has been shown to be very limited in effectiveness. Alcohol advertising in magazines, music, and the media can be made better by the alcohol companies, and society could do a better job of protecting our children.

Discussion included:

- *What prevents the alcohol industry from going through the Internet or satellite TV?* Nothing. There is no oversight of the Internet and only limited oversight of cable television.
- *Is there evidence that involving parents in knowing where their children are is helpful (e.g., as in recent ads advising parents to proactively ask their children's plans upon going out)?* From a public health research perspective, there is no evidence available on the effectiveness of that kind of approach. While these kinds of initiatives seem to encourage parents to supervise their children better, they have not been evaluated. A better job must be done to pre-test these messages or to evaluate them as they are implemented. Parents should be aware that alcohol and alcohol advertising are much bigger deals in their children's lives than it was when they were children, and they should let policy makers know that they oppose this harmful manipulation of our children.
- The fact that NAS made a recommendation is unusual. They found more evidence that adult behavior could be changed than children's, part of the reason they recommended an adult campaign, but they encouraged the pilot of a children's campaign as well.
- *Is there any evidence that media literacy campaigns work?* Media literacy is the ability to access, analyze, evaluate and communicate information in various formats. Media literacy programs educate students on how to critically examine advertisements and other kinds of media. A forthcoming NIAAA study done by the Rand Institute includes a media literacy intervention. That will provide some evidence on that intervention but, while media literacy might be useful, it is not sufficient.
- Dr. Caetano stated that this was a part of a much larger problem, and adapting to that larger vision is necessary to be maximally effective. It is easy for the industry to negate its responsibility. In view of the fact that no one lives in a vacuum, part of the Task Force's work should be to shift the perspective of FAS beyond the individual women involved to the social context that breeds the problem, and to highlight the general responsibility for FAS. Dr. Jernigan related that one reason that there has been no class action or personal injury suit for FAS damages stems from the 1990 case of a pregnant woman in Washington state. Her personal life was made the subject of the case and the blame was placed solely on her.
- The amount of money spent by the alcohol industry is hard for the beneficiaries to give up (e.g., tax revenue, stadium construction funded, etc.). But the point was made that the level of tax revenue lost during Prohibition was never regained when it was repealed. Research on taxes and alcohol prices indicate that if they were raised to a comparable level, that revenue would be very significant and could fund public health work.
- Mr. Hacker also reported on the CSPI's campaign in the last year to remove alcohol advertising from sports events on television. Their first target is the use of alcohol advertisement and college sports, the least defensible area. They are targeting college presidents and athletic directors. To date, 20-30 (~24%) NCAA team schools have pledged to eliminate alcohol advertising in their college broadcasts and

to participate in eliminating it from NCAA tournaments. The CSPI is trying to find out how much the NCAA broadcasters depend on alcohol advertising, but since alcohol ads constitute only 5% of college sports dollars, it should be replaceable by other sources. The programs that did eliminate advertising had no resulting loss in revenue. The broadcasters just have to work harder to replace those revenues. The CSPI is trying to identify those replacement sources as well. Dr. Jernigan indicated that the leading coaches hate the involvement of the alcohol industry in college sports, but this was not true for the smaller schools.

- There is no research being done to indicate whether the increased overexposure of young women is paralleled by an increase in FAS. This could be studied in the context of the natural experiment going on with the advent of alcopops and the huge increase in the amount and sophistication of alcohol advertising in the last few years.
- The 29% increase in binge drinking episodes is even more troubling since the NIAAA estimate of \$180 billion does not include many of the societal costs from alcohol. CDC's Dr. Brewer mentioned a study in Madison, WI, that is underway to determine any impact from that increase in binge drinking on the law enforcement community, as just one component of the social cost.
- Dr. Brewer asked if reducing the underage exposures could be done without also reducing the advertising to the older age group. Dr. Jernigan responded that television will be the toughest arena in which to work due to the wide array of programming. But CAMY will keep mentioning the three cable channels (VH1, BET and Comedy Central) responsible for the most youth overexposure to the FTC. This could reduce their alcohol advertising, as was successfully done with MTV's withdrawal from that market in the 1990s. Detecting and correcting overexposure is very possible in magazines. CAMY also does its research by individual brands, something necessary to counter the industry's averaging of their brand profiles to confuse matters.
- No one has researched the impact of the shows' content to look for messages coming through the program beyond the commercial. CAMY is a public health pioneer in this area but no one else is systematically monitoring this. CAMY looked at product placement on broadcast TV, but there are no standards for such measurement. Product placement within shows is a new industry tool that bears attention.
- The difference between restriction of alcohol advertising and tobacco company ads is 25 years. The law was different then; there was virtually no protection for commercial speech, which arose in the mid-1970s. There also was a different political climate then. At the time, based on the Fairness Doctrine, the FCC required the media to air one free counter ad to 4-5 tobacco ads. The counter ads were so effective that the tobacco industry withdrew their advertising from TV entirely.
- The individual perception (including that of marketers) of alcohol advertising lags behind the public health perception. The latter changed from seeing drinking as an individual problem to be addressed on that level, to an environmental problem to be addressed in a social context. The industry's message is still to advise adults to "talk to their children." But at a recent industry meeting on self-regulation, their discussions indicate that they are aware that society holds them responsible for their

advertising. This is odd in a group that denies any association between advertising and consumption.

- Dr. Babor reported, after reviewing the literature on alcohol policies, that the most effective interventions tend to be unpopular; and the least effective, popular. That balance needs to be altered. The least effective approaches are individually oriented and based on simple interventions, but also use faulty assumptions of what governs people's behavior. The industry cites individual responsibility, but that is not necessarily true for adolescents and young women. For them, it is more likely that the social environment, product access, and the modeling presented to them as a social group, are more important contributors than information on rare events, such as FAS. If the balance is to be altered, attention must first be paid to the evidence for the effectiveness of population-level approaches. That might include systems, such as health care, to get the interventions to the population level where they are likely to have an effect, rather than worrying about changing each individual's behavior.
- Dr. Caetano agreed. Education alone cannot be assumed to be all that is necessary; it is only one component. Youth uninterested in what their teachers have to say go home and are more affected by the glamorous presentations of drinking they see on television.
- Dr. Babor reported that he had misinterpreted the cost-effectiveness data in the latest article in *Addiction* (note: see page 22). He reviewed what the WHO had shown to be the most cost-effective strategies to prevent years of functional living lost. The lowest cost-effectiveness score was alcohol-related taxes, followed by advertising bans, reduced access, general practitioner advice and random breath testing. Population approaches like ad bans are cost effective. Rather than banning ads, the media should be used to educate children about what the ads are trying to do, but that takes time and costs money. All these things need to be taken into account. A variety of different policies on the individual and population level are effective. While the less effective interventions should not be abandoned, they should not be favored one over another, especially if they take resources away from another.
- Rather than the negative "worst practices," the "less effective" terminology was preferred for those that produce no negative impact. Dr. Berner thought that attention should not focus on FAS or FAE as indicator outcomes, since they are rare and difficult to ascertain (particularly FAE). And, rather than cost-effectiveness estimates, he would look at trends. Dr. Babor agreed that the focus should be more on the population at risk and on women at high risk of drinking than on the rates of FAE/FAS, but the research techniques are not yet capable of that level of refinement.
- CDC's Dr. Shahul Ebrahim noted the Global Fund for HIV/AIDS and the popularity of addressing the obesity epidemic, even though alcohol is the third to fifth cause of DALYs (more so in South America and Africa) in the world. He asked why alcohol effects had garnered so little public health/lobbying interest.
- Dr. Jernigan reported that while the WHO is interested in the issue, they only have one employee devoting 40% time to alcohol issues. At the World Health Assembly's

last session, a resolution was passed for the first time that included the word “alcohol,” but only after there were efforts against passing the resolution. Dr. Jernigan hoped for more attention in future, but there is little official mandate for that now. The WHO only addresses it because they know it is good public health. Publications could help keep the issue alive, such as the hoped-for release of the 2002 meeting on food, tobacco and alcohol held in Italy, and an article co-authored by him and Dr. Babor on marketing and public health. The WHO also issued a project report on alcohol and gender that looked at the neuroscience aspects; and there are some efforts to improve the epidemiological knowledge base on alcohol use, especially in developing countries. But given the magnitude of the problem and its role in the burden of disease, the resources devoted to it remain minuscule.

- Dr. Sokol called for this Task Force’s attention to risk drinking (not all drinking) from both the individual consumer and the health professional perspective.

Moving Research into Practice: Challenges to Successful Implementation of Prevention Strategies in the Field

Kristen L. Barry, PhD, from the University of Michigan Department of Psychiatry and National Serious Mental Illness Treatment Research and Evaluation Center, discussed the challenges of moving alcohol research into practice. Dr. Barry presented a spectrum of interventions that have been developed to address different patterns of alcohol use. Different interventions are appropriate based on an individual’s level of use (e.g., light to moderate drinker vs. drinker with alcohol problems or mild dependence).

About 5-15% of women of childbearing age have some problems with alcohol use. Approximately 5% of 18-24 year-olds and 3% of women 25 years binge drank 5 or more times in the last 30 days (National Household Survey, SAMHSA, 2002). Twelve percent of pregnant women drank in last month (SAMHSA, 2002).

In a University of Michigan study of pregnant women (n=1131), 15% had used alcohol during pregnancy. Only half of the pregnant women who reported using any alcohol during pregnancy indicated that their physicians talked to them about their alcohol use. Those 50% reported that they were asked something about their alcohol use by a provider, were given an advice message, or changed their alcohol use during pregnancy (generally stopped drinking). The physicians were most likely to speak to women from lower socio-economic backgrounds, minorities, and women with less education.

Health care delivery research indicates that clinics/providers are very slow to implement evidence-based screening and behavioral interventions. The rates of detection, brief intervention, and referral for non-pregnant women are low, and lower still for pregnant women. Simulated patient studies show that women are less likely than men to be screened, intervened with and/or referred. Barriers include provider issues such as lack of knowledge, comfort with conducting screening and brief interventions, clinical practice time crunch (physicians now can spend only ~10 minutes per patient to maintain a cost-effective practice), and reimbursement protocols that are oriented to

procedures rather than prevention. External issues such as state laws, reporting regulations, and patient issues (fear of legal repercussions, social stigma, and lack of internal and external resources) are also barriers to implementation of alcohol prevention measures.

The CDC, SAMHSA, NIAAA and ACOG have all released evidence-based recommendations on the use of protocols for universal screening, brief interventions, and referral to treatment. ACOG's 2004 ethical rationale for these protocols covered the components of beneficence (therapeutic intent), nonmaleficence (do no harm), justice (access to care and fair distribution of resources, e.g., universal screening); and concerns for confidentiality (disclosure issues).

Issues raised for the Task Force's consideration relative to crafting recommendations on implementing interventions included:

- Screening: who should be screened and where?
- Co-morbidities (depression, anxiety, distress)
- Types of interventions: Targeted research is needed on these interventions among pregnant women. Effective interventions for alcohol use and/or contraception for women at high risk need to be replicated. Other research topics include the use of step-wise interventions; use of technology for screening and interventions, and the bundling of interventions.
- Training health care providers: who, how, when, where?
- Reimbursement system

Benefits/cost analyses done include:

- Brief intervention: A benefit/cost analysis done by Fleming et al (2002) indicated a \$205 total cost per patient for brief intervention which includes both clinic and patient costs. The cost advantage between the intervention and the control group was significant for medical ($p=.02$) and motor vehicle ($p=.03$) events. Overall, the analysis suggested a \$43,000 reduction in future health costs for every \$10,000 invested in early intervention.
- Other costs to consider included those for universal screening and treatment.

New Directions for Screening and Brief Intervention include:

- Use of innovative technologies, such as: tailored computerized screening and brief intervention messages; interactive voice recognition technology (tailored audiotape for questionnaire and advice delivery in a fast-paced setting); web-based interventions for special populations (e.g., adolescents, college students, homebound); "video doctor," and phone-based counseling. Research indicates that brief treatment and pre-treatment interventions can have positive effects, but how to deliver and pay for them requires discussion.
- Targeting special populations, such as pregnant women/new mothers, adolescents, and minority populations. Examination of co-morbid and mental health conditions

(e.g., depression, bipolar disorder, schizophrenia) should also be considered.

- Step-wise interventions/strategies for those who do not respond to the first prevention messages, brief advice or brief interventions (e.g., brief therapies, case management strategies).

Areas to consider for recommendations for prevention, early intervention, and referral for treatment include:

- Training health care providers in screening, brief intervention, and referral systems for individuals/families. This training would include primary care providers, nurses, nurse practitioners, physician assistants, OB/Gyns, social workers, psychologists, health and peer educators, addiction specialists, and students of all the above.
- Research funding: directions for new studies.
- Policy process: institutional, state, and national level, to advocate for the health care needs of patients.
- Reimbursement issues.
- Use of universal intervention strategies, or selected interventions for those at some risk, and indicated for those most at risk. Where to start?

Other areas to consider for recommendations include advertising, laws and legal restrictions.

Discussion: Defining the FASD Prevention Agenda

- *Are there data to indicate what drinking relates more to FAS (e.g., at home, a bar, a party), since response strategies cut across demographics differently?* Dr. Morris commented that mothers of babies with FAS represent every venue in which alcohol could be consumed.
- There is no established dose-response relationship, according to Dr. Calhoun, although twin studies indicate a number of factors involved in fetal response to alcohol. Binge drinkers are at most risk, but some research also indicates that even lower amounts of alcohol at particular times in pregnancy will produce a spectrum of disorders that differ among the trimesters of pregnancy. Some contend that any drinking in pregnancy, even at low levels (1-2 drinks at time or a week), can produce some cognitive deficits over time, and that children are smaller, even measured later in life. The twins research also shows that the more alcohol consumed, the greater the effect on the child, something also shown in epidemiologic data.
- Dr. Caetano described the conduct of an evaluation of a brief intervention with emergency populations. These were conducted by trained interventionists, because trauma nurses typically do not adhere to study protocols. This suggests the importance of training health care workers in alcohol screening and brief interventions.
- The wedge concept in Dr. Caetano's presentation was based on information from the IOM report on alcohol. It shows the enduring effect of alcohol exposure and

graphically characterizes the types of drinkers from a population point of view. In the 1990s, CDC funded a study focused on women at high risk for an alcohol-exposed pregnancy versus a population approach. This resulted in Project Choices which is producing positive outcomes. The question that remains is where to direct prevention efforts?

- Referring back to Dr. Caetano's comment, Ms. Mitchell reported NOFAS' similar experience with ER nurses' trouble sticking to a screening instrument. But NOFAS also found that even without a protocol, when hospital nurses empathetically ask women about their drinking, the women were more likely to be honest and respond. That is quite different from gathering data for a research study, but it is important to recognize that these nurses can play a key role in identifying at risk women. She added that the women at highest risk are those with alcoholism, and their stage in the disease process predicts whether they drink at home or at a bar. When they lose resources to go out, they will drink at home. She asked if the Task Force was reluctant to discuss alcoholism rather than binge drinking, etc. Dr. Floyd responded that recent NIAAA definitions have delineated alcohol abuse and alcohol dependence, and the latter has been equated to alcoholism. Those defined as dependent are known to abuse alcohol in a harmful pattern, but would not meet DSM definition of alcoholism.
- Dr. Sokol cited good evidence from human research for a clinical teratology very similar to that in animals. Heavier drinking produces a greater proportion of those affected and has more effect. In that regard, FASD is a very useful concept to reflect the continuum of exposure causality. While the concept that any drinking produces an effect might be a good public health approach, realistically, the lower level of drinking in our society is probably 5-10 drinks/week, and those are usually sequential. While much of the drinking done by women is at home, they also go out, and most have more than one glass of wine a night. Another policy factor to consider is susceptibility; what might be good (or not harmful) for one person is not so for another. The continuum of alcoholism has to extend all the way down to abusing drinking. A developing system is much more susceptible than that of a grown woman, so an exposure that is not a problem for a 25 year-old women in her first trimester might be so for a developing fetus. An intervention's focus will have to be on where the effect is desired. An approach might *start at the high end, where there is high prevalence of adverse outcomes. But these are also the hardest people to impact, so perhaps the approach should begin further down on the pyramid. His bias was for selective intervention with someone drinking, or at risk of drinking, prior to conception.*
- Another approach, as opposed to focusing on one end or the other of the wedge, would be to look at this broadly and perhaps develop a multifaceted approach (e.g., strategies for the dependent and abusing drinker, as well as binge drinkers and those in the low risk category who may have a child with partial FAS).
- NIH's NESARC research data indicate that alcohol dependence is a developmental disorder which begins for many at age 15 and then peaks at 18 and again at 21. Those ages would include college students and young professionals. And, since the brain continues to develop to age 21, NIAAA is also studying the impact of alcohol use/abuse on the brain. Aside from fetal effects from alcohol abuse during

pregnancy, alcohol also impacts the brain in adolescence and young adulthood. The main barrier to screening as a strategy is that even trained professionals do not want to screen in the absence of treatment referral sources (e.g., for the alcohol abusing college student). Abusers' rates of relapse and treatment failure are similar to those living with a chronic disease and need treatment over time. These groups need to be identified in the pre-alcoholism stage, but few states have the treatment resources to address them.

- Dr. Carmichael Olsen supported the idea of recommending strategies at multiple points of the pyramid. She suggested that the Task Force consider outcomes that reflect real progress, such as a decline in the reported drinking in pregnancy coupled with lowered incidence of full FAS. CDC's PRAMS data could be used to track drinking in pregnancy. Washington state used these data and established a diagnostic clinic system and diagnostic screening process that showed reduced FAS incidence. The Task Force could recommend the use of existing data gathering and tracking instruments and follow their recommendations' progress to assess their impact. Washington does have a system in place to provide services to alcohol abusing women; however, as in other states, they do not have a good system in place to address the needs of high-risk abusing youth.
- Ms. Mitchell raised the importance of family history when assessing women for alcoholism or alcohol dependency. The latter is not evident until the middle stages of the disease. Until then, health professionals often miss the link to treatment, perpetuating the stigma and the myth that women can stop on their own. She insisted that we keep in mind that alcoholism is a disease. While she appreciated the trend to looking at this as a systemic, societal problem, the women at highest risk should not be overlooked.
- Dr. Deborah Stone, of the FASD Center for Excellence, indicated that 10% of children in North Carolina have ADHD. She wondered how many of these children may have been exposed to alcohol prenatally. She also mentioned that certain messages produce the wrong assumptions among women. For example, one myth is that a woman with no family history of alcoholism can have a drink every night. This infers that some women are immune to alcohol and can drink, which is untrue.
- Dr. Cohen stated that there are few state-level treatment services for women abusing or dependent on alcohol. Of those that do exist, few address only alcoholism; most involve drugs and alcohol, and most are geared to men. Few enroll women and fewer still accept women with children, pregnant or not. Even New Jersey, which ended up with the biggest FAS prevention initiative ever, was the result of a "non FAS" issue. That is, it stemmed from a court order related to child abuse, which reformed the child welfare system and opened 2500 new treatment slots. The pregnant woman remains the highest priority, but the second priority is for women with any child under the state child welfare system. About 90% of the child welfare system is made up of women. *Perhaps the place to start finding the alcohol-abusing women is in such organized systems.*
- Dr. Babor commented that the term "alcohol dependence" evolved from the psychological disorder previously known as alcoholism. He agreed that there is a spectrum of drinking patterns in which few develop into full alcoholics. The disability spectrum resulting from alcohol use is important, but the most efficient use of

resources remains a priority. He suggested:

- Identification of the different risk groups (i.e., alcoholics or alcohol-dependent women). Those with severe alcohol problems and most likely to present with a fetus or child are most at risk. These women's characteristics (e.g., age, SES, education) have to be determined to learn how to intervene with them.
 - Identification of alcohol-abusing women. These are greater in number but have a lower FAS risk and still need interventions. Determination of how to find them, their characteristics, age of pregnancies, and intervention points, is needed.
 - What is the larger group of women at risk? How can their lower, but still significant numbers be identified and their cases prevented?
 - Factors related to intervention include access to (not the type of) treatment. Outreach is needed. If the woman is not chemical-dependent or in drug/substance abuse treatment, the outreach may come from the family health care provider or the family agency social worker. Treatment comes from a spectrum of providers.
- Increased resources are needed, perhaps through taxes or some other route. *A matrix of risk groups and interventions could help begin the identification of interventions relevant to different populations.* The Task Force should not only recommend possible strategies but also indicate how to implement the intervention.
 - The triangular flow chart should be inverted to show the prevalence of FAS.
 - Alaska discovered that the early most teachable moments to educate women about the dangers of alcohol was early in pregnancy. The key to preventing FAS was early intervention among high risk children even before they attended school, and the treatment received by their care givers. Almost all the woman who said they could not stop drinking were abused as a child by an adult who used alcohol to facilitate the abuse. That is not something the 12-step program was designed to treat. Treating their problem as unique in a residential program where they could bring their children was far more successful than expected. While it may not have affected the present pregnancy, it would do so for the subsequent ones. Alaska has been tracking the trends of alcohol use in pregnancy and FAS since 1994 to inform the conduct of their programs.
 - Dr. Schad agreed to the large spectrum involved with FAS and the need for more treatment sites. South Dakota has no treatment available in the western part of the state where nine Indian nations reside.
 - Dr. Carmichael Olsen described a recent Washington state study that highlights the importance of multi-level preventive strategies to reduce FASD rates and also assesses the effectiveness of these efforts by evaluating state FAS prevalence rates and alcohol consumption rates during a 5-year period. Washington state has provided a wide variety of prevention strategies ranging from public education to direct intervention with high-risk women. In addition, they have established a network of diagnostic centers and developed diagnostic tools and methods to help identify children with FAS. The state also has the infrastructure in place to assess

FAS prevalence and alcohol consumption rates (through state PRAMS data). Legislative efforts were also part of this multi-level prevention strategy. Dr. Carmichael-Olson stressed the need for multi-level strategies, especially those that offer the best evidence at different levels of alcohol use, and those that are able to stop risky drinking in pregnancy.

- Ms. Mitchell stated that alcohol-abusing women who actually are alcoholics are often not diagnosed until their 30s. Better early identification of alcoholics by physicians is needed in order to get them into treatment earlier. Most mothers started drinking very young but were not identified as alcoholic until they had several children. She knew of few mothers who had children with FAS only from drinking in college.
- The NIAAA has defined binge drinking as 4 drinks at a time on any occasion in a two-hour period or more. This is a group needing selective intervention not the women who drink in moderation (<7 drinks in a week). But the reality is that people do not just have one drink a day. Better guidance on “moderate drinking” is needed. Who should have priority for an intervention?
- Dr. Floyd suggested as a starting point to target the women of childbearing age who engages in risky drinking (i.e., >7 drinks a week and/or binge drinking).
- *Establishing a level or pattern of drinking as a marker that would suggest a particular intervention strategy was of interest.* One thing to avoid in determining this is mixing survey assessment techniques with clinical instruments.
- Dr. Mengel supported a focus at the top of the pie, where the data are most plentiful and the syndrome is most prevalent, targeting non-pregnant women of childbearing age. Most physicians do not detect problem drinkers. The quantity and frequency questions stated by Dr. Floyd have to be asked.
- Dr. Sokol recommended, with pregnant women, doing the screening questionnaire first to avoid as much denial as possible, followed by the quantity and frequency questions that Dr. Floyd mentioned. In an as-yet unpublished study they did, the women were first asked about quantity and frequency, producing more denial. It could be done differently, perhaps using the AUDIT. He recommended that obstetricians do a T-ACE survey of four questions and then ask quantity and frequency questions. *Either a positive T-ACE or above-normal quantity/frequency information, using NIAAA criteria, could be used to identify women at risk.*
- Dr. Berner reported Alaska’s protocol of asking about alcohol use during the prenatal exam. They tend to get more information from women about their alcohol use after labor. A higher percentage of women reported drinking while pregnant during labor, thinking that some last-minute intervention might help, and are less willing to either deny or conceal it than they were earlier in pregnancy. Not surprisingly, women detected this way also tended to be those with the other high-risk indicators cited earlier. Self-reported early prenatal screening data are helpful but should not serve as the final assessment.
- Dr. Boyle summarized that the x-axis of the prevention matrix would reflect different groups based on level of alcohol use and the y-axis would include the spectrum of interventions ranging from universal to indicated. The best practices suggest interventions for higher risk alcohol-using groups, such as taxes or changes in points of sale. She asked what the Task Force would recommend for universal

approaches, especially for the lower-volume and lower-frequency but still at-risk drinkers, while also keeping in mind the need to focus on FASD. The interventions of this huge problem require prioritization. Some interventions, such as those with more palatable political and economic costs, could rise to the top. Some may be more likely to impact the population or effect outcomes. Which should be addressed first, or should this should be done comprehensively?

- Dr. Wright referred to Dr. Babor's list of best practices, but noted that, although broad and effective, they do not address the media challenges outlined by Dr. Jernigan or the social issues, such as depression or sexual abuse, that lead to abusive drinking.
- Dr. Babor noted that most states have server training interventions (e.g., to recognize intoxication), but it is doubtful that they are specifically taught to recognize and/or intervene with pregnant women. There would be no added cost to include that focus in server training curricula. And, while there is no evidence that this is a best practice, it offers a clear benefit. However, there was general agreement from the Task Force that asking a server to determine if a woman is overweight or pregnant was asking too much and may not be legal.
- Once the risk groups have been identified and assessed, suitable interventions could be tailored. Opportunistic screening through primary care providers, OB/Gyns, and others should be done to reach the risk groups. Restrictions to alcohol's general availability (e.g., hours of sale) would be Dr. Babor's first option, followed by tailored limits for populations at risk. There are many more interventions than the top ten he had listed.
- It was noted that none of the top ten actions seemed to apply to college students' binge drinking, other than the minimum age requirement.
- Dr. Calhoun indicated that women have been educated about the dangers of drinking during pregnancy. Perhaps it is time to begin educating men as well.
- Dr. Caetano recommended a report on FAS with the same subtitle as the IOM report on underage drinking, "A Collective Responsibility." This would reinforce that the roots of the alcohol problem also involve the industry and society, particularly with regards to underage drinking.
- Ms. Ohlemiller cited this conversation as a demonstration of the importance of having a pragmatic review of the best practices. The inclusion of capacity building is also critical for any statement issued under the Task Force's name. She also called for greater inclusion of the mental health community which, when FAS was presented in her state, asked why they had not heard of it before. They could be seeing these high-risk women already, particularly those dealing with the early abuse mentioned by Dr. Berner.
- Dr. Stone agreed that people just do not know about FASD. The FASD Center for Excellence trained over 8,000 people last year. Many people think that FAS is a drunk baby who will recover and catch up developmentally by age 7. She supported issuing a strong message to convey that FASD is a life-long condition.
- Dr. Babor suggested that the Task Force decide if the focus should be on women of childbearing age at any time or on those most likely to be at risk. As the members

try to fit interventions to different risk groups, consideration of demographic characteristics and other key indicators is needed. These can be found in the epidemiologic data. These include risk characteristics such as women with prior FAS pregnancies who are likely to have another one; women of higher education being more interested in health-related information while those of lesser education attend more to the advice of a health expert or doctor; and the fact that the average age of pregnancy is rising to the mid- to late-20s. These kinds of factors could influence when to intervene and what interventions are most appropriate.

- Dr. Babor reviewed the strategies with evidence of effectiveness such as Alaska's experience with prohibition, for example, which provides a local option for communities to vote to not serve alcohol. The risk groups he would focus on were: women with a syndrome of alcohol dependence; women who periodically abuse alcohol or harmful drinking; women who exceed NIAAA or USDA guidelines for harmful drinking, and women who are likely to become pregnant. Possible interventions could include:
 - Screening to identify cases, detect alcohol abuse, and identify groups exceeding the NIAAA/USDA guidelines. The cost effectiveness of screening in various settings can be analyzed.
 - Treatment of women with alcohol dependence. Programs for pregnancy and parenting women can isolate a woman from alcohol for the entire pregnancy, and if combined with safe housing, etc., the woman can be monitored and followed.
 - Self-help groups would be limited to women with alcohol dependence only.
 - Lowered alcohol content -- Population rates of alcohol dependence decline with changes in the alcohol content of the beverages sold. A good deal of evidence on FAS comes from toxicology research regarding the effects of alcohol during pregnancy. Lowering the alcohol content of beverages is likely to lower the exposures of women drinking and therefore lessen the chance of prenatal alcohol exposure. An example in the 1980s was Massachusetts' mobilization against highway deaths; the alcohol industry lowered the alcohol content. Anything that lowers the population's exposure to alcohol is an intervention that can save lives.
 - Taxes and pricing -- The higher the price, the less people drink. Discount drink promotions encourage drinking and substantially increase intoxication levels.
 - Enforcement of on-premise policies and interventions by servers trained to know what alcohol levels induce intoxication. But servers are not taught about the effects from moderate alcohol levels, or about invisible intoxication. Raising that point would be an interesting approach.
 - Advertising bans/controls -- The industry's own codes indicate that it is irresponsible to depict alcohol in ways that are attractive to young people, but they seem systematically to violate their own guidelines. *Asking the industry to enforce the guidelines to which they have already agreed could go far to remove their modeling/suggestion for women to drink.* Their

approach emphasizes the younger age groups; ads with men or women in their late 40s or 50s are not seen. An emphasis on the need to remove role models indicating that heavy drinking is acceptable would in itself target the high risk groups of heavy and dependent drinkers. MADD's success in raising the visibility of the problem of drunk driving and changing enforcement policies is a model that can be used for FAS. Changing society's opinion of the problem is important, as underage drinkers also include women of childbearing age with potential exposures to a fetus as well as the woman herself. Raising awareness to gain society's support is important.

- Initiative approaches to address underage drinkers could include raising taxes, as done for tobacco, and conducting a population level approach to mobilize popular opinion behind that, perhaps in collaboration with MADD. The erosion of drinking policies, as seen in Russian, Poland, and the Eastern European countries, brings about tremendous increases in consumption.
- Reviewing the strategies in the proposed matrix should occur, examining each area to discuss the advantages and disadvantages and its relevance to prenatal alcohol exposure.
- Dr. Miller pointed out that even very successful interventions offer small change increments (at most 10 to 20%). She warned that expectations must be realistic. It may be that significant effects would be the result of synergistic, cumulative interventions.
- It was noted that educating people about the issues of FAS must continue. Even a woman who is a low-risk drinker needs to know that she needs to stop drinking when she becomes pregnant.
- Dr. Floyd said that the goal is to prevent alcohol-exposed pregnancies, focusing on women who are fertile, drinking at risky levels, and not contracepting effectively. A Virginia Commonwealth University study, based on Project Choices methodology, involved college-age women who drank at risk levels. They were asked to reduce their high-risk drinking levels, increase effective contraception use, or both. Most chose contraception use. Technically, if a woman uses contraception effectively or does not drink, she is not at risk for an alcohol-exposed pregnancy.
- Dr. Boyle commented that while that study was a brief intervention, its intent was to reduce the risk of an alcohol-exposed pregnancy, not to reduce FASD. While high school education on FASD may not necessarily change behavior, but it could at least ingrain the prevention message to not drink while pregnant that could be remembered later.

Business Items

Update on Surgeon General's Advisory: Dr. Floyd reported that a month earlier, Dr. Gerberding's office had resubmitted to the Surgeon General's Office the Task Force's request to reissue the 1981 warning about drinking during pregnancy. The Surgeon General's Office asked for more information regarding alcohol threshold levels known to

negatively effect the fetus. CDC responded that no threshold level was known. The Surgeon General asked for more information which was provided with further input from the NIAAA. CDC has not yet heard back from the Surgeon General's Office regarding this request.

Reauthorization of the IDEA (Individuals with Disabilities Education Act): Dr. Cohen worked with NOFAS and the Arc to urge inclusion of FAS in the list of conditions outlined in IDEA; however, the bill was already close to passing and it was unlikely that any legislator would want to add another discrete disorder. NOFAS and the Arc advised her to work with the Department of Education (DOE) as they develop the administrative regulations for the reauthorization. The early intervention component of the Act, Part C, covers eligible children from birth to age 3 years. In the previous iteration of the IDEA, the transition plans for coverage from age 3 to kindergarten (age 5) were not working well. Not all children were preschool handicapped-eligible for services. The new law gives the states the authority to merge those programs, so that all children can receive services from age 3 until they are in school (and then subsequently covered by Part B). The inclusion of FAS in the IDEA was to be further discussed in the next day's Post-Exposure work group meeting. The Arc's Governmental Affairs office was pleased that the IDEA was passed, even though it is not perfect. It excluded some processes that the Arc and other representatives of people with disabilities wanted, such as an appeals process for those not covered.

FAS Teacher Certification: Dr. Schad reported that teacher certification issues are not addressed at the national level; rather, they vary state by state. Dr. Schad learned that his state's Office of Education did not provide teacher certification on FAS. Black Hills State University was recently funded by CDC to develop a teacher education curriculum. He has met with a variety of individuals in the state and has gained their support in these efforts, including circuit courts' judges, the nine state tribal units, and Black Hills' Dean of the College of Education. The Vice President of Academic Affairs agreed that if the pilot project is successful, Black Hills could offer a one-hour course based on the pilot. Dr. Schad also met with the state's Secretary of Education for preschool through 12th grade, who also was supportive of these efforts. Dr. Schad has also met with the South Dakota Board of Regents which governs the state's academic affairs and requested permission to offer this course beyond the pilot's two year term. This coming Thursday, he is scheduled to discuss the FASD curriculum with the Department of Education in Washington. He agreed to e-mail the results of that meeting to the members and to report further at the next Task Force meeting.

Agency/Organization Updates

SAMHSA. Callie Gass and Deborah Stone from the FASD Center for Excellence reported on recent Center activities. SAMHSA awarded contracts to state juvenile justice systems to integrate FASD practice into their systems of care. The first 20 contracts were awarded before Thanksgiving and another ten states will be awarded in late December. The purpose of the contracts is: 1) to test whether evidence-based practices can be integrated into these systems to produce better results for FASD, or to prevent an alcohol-exposed pregnancy, and 2) to see if the system can absorb the change. This will be evaluated on two levels: a) the cross-site success of integrating

the practice (e.g., routine screening of women presenting for alcohol abuse), and b) effectiveness of the intervention itself.

The first 10-months of these awards consists of a planning period and will include assembling an advisory group/Task Force, conducting a needs assessment, and developing a strategic plan/work plan. Upon approval of activities, budgets for these activities will be proposed. The competition for these contracts was much higher than anticipated, with submission of 19 qualified applications seeking the five slots.

The FASD Center for Excellence Steering Committee met recently and discussed some of the same questions raised by this Task Force regarding substance abuse treatment and mental health. In particular, they discussed how to determine the population of interest for prevention work. Their approach was a little different since they were looking at women who are already seeking treatment for mental health or substance abuse problems, or presenting at an MCH treatment center. The Steering Committee began to identify those sites where such women at high risk are, and/or those who already have had a previous alcohol-exposed pregnancy.

FASD Center for Excellence training activities are ongoing. The Center held a Women's Summit with NOFAS. With the help of University of Washington and NOFAS, a subsequent video, *Recovering Hope*, was produced by and for mothers of babies with FASD. It should be available through the National Clearinghouse shortly. The women talk of their experiences of being pregnant but unable to stop drinking, about not knowing what to do, and about hope. One woman who participated in the video decided after the Summit to have her own children evaluated. The video narrative is free and is presented in two parts. To date, 900 copies have been distributed and another 13,000 are being copied. It can be ordered from the SAMHSA Website through the "video" link. It already appears to be an excellent outreach tool, although it has not yet been formally evaluated. Designed for use among women in treatment centers (many other uses have been suggested), it also has had an effect on the policymakers who have viewed it.

ICCFAS. Dr. Sally Anderson, the new Executive Secretary of the ICCFAS, reported on the group's role to improve communication, cooperation, and collaboration among the disciplines and federal agencies that address health, disabilities, education, developmental disabilities, alcohol research and social services. The agencies participating in the ICCFAS were outlined, many of which focus on service provision (Education, Justice and several DHHS entities). Other partners could include the National Institute on Drug Abuse, the National Institute of Mental Health and the Department of Agriculture.

The 1996 IOM report formed the theme around which the ICCFAS works: intervening with children and families affected by prenatal alcohol exposure, improving methods for diagnosis, increasing research in FAS etiology and pathogenesis, preventing alcohol use during pregnancy, and increasing information dissemination.

The ICCFAS has not met for awhile, but will meet several times in the next few months

to write their five-year progress report and to develop a strategic plan for the next few years. Among the latter are opportunities for advancement, particularly collaboratively.

- Behavioral research. The American Psychological Association will announce the first decade of the 21st century as the “Decade of Research,” after the 1990s “Decade of the Brain,” which focused on understanding brain function. This will emphasize behavioral research, models and promising new therapies, which the ICCFAS hopes can be applied to improve the functioning of children with FAS and their families.
- Education. The First Lady’s agenda on educational opportunities for all and reducing juvenile delinquency should also present possible opportunities to educate about FASD.
- Justice. The ICCFAS hopes to work more with Juvenile Justice to address these problems and to identify children damaged by ethanol exposure early. Progress has been made in developing biochemical markers of exposure to ethanol.
- More mother-friendly screening methods are needed, as are diagnostic measures to better identify affected children early. Advanced behavioral techniques for infants and toddlers may be applicable to FAS interventions.
- Improving diagnosis. Also desired is the need for more research on FAS etiology and pathogenesis with which to develop therapies, whether behavioral, biochemical, or dietary. Greater understanding is needed of the role of genetics, proteins, cellular metabolites, etc., as well as techniques and technical analysis to explore biomarkers of exposure or nutritional deficits. All mothers who have used alcohol have not had children affected by prenatal alcohol exposure; why is this? What is different about these mothers may help guide treatment and prevention efforts.
- Increasing community education and information dissemination. Increased emphasis is needed by all federal agencies on collaboration/cooperation, nationally and internationally, to increase the synergy of combined work (e.g., discussion by teleconferences and website links, etc.).
- Prevention of drinking during pregnancy. This includes translating research results into practical application for treatment centers and other settings, including population-specific approaches.

Dr. Calhoun added that the ICCFAS used to meet several times a year before the FAS Task Force was formed. The latter now meets twice a year, as does the Steering Committee of the FASD Center for Excellence. That totals six meetings per year, along with the routine work of issuing RFAs, analyzing results, disbursing funding and sharing conclusions about funded work, etc. NIAAA funded \$16-20 million to FASD research, mostly using animal models (e.g., what starts/stops cell migration with ethanol exposure and pharmacological therapies for fetal injury). NIAAA’s work began before functional MRI imaging technology. The field has come a long way, and the ICCFAS had to be reconvened to assess the status of the field. The DOE’s Office of Rehabilitation and Special Education and DOJ’s Office of Juvenile Justice and Delinquency Prevention now are also very interested in FASD. Congressional language also recently was presented that will probably raise the interest of other organizations in participating in

the ICCFAS. They look forward to determining future activities and will welcome this Task Force's recommendations.

NIAAA also continues to fund collaborative initiatives on FAS, now involving 4-5 other countries as well as the U.S., to assemble the knowledge and to explore how to transfer animal research to humans. The principle investigators of NIAAA's 13-14 related grants have met to share their experiences and progress in a coordinated manner. After the 2½-year pilot's term is over, these will be re-competed for renewal. Part of the requirements for that will be the demonstrated formation of a collaborative body. Researchers abroad have larger populations of individuals with FASD than does the U.S., and their core diagnosticians and behavioral scientists are coordinating with NIAAA work.

NIAAA and NICHD also funded another international study on prenatal alcohol consumption, stillbirths and SIDS, to follow some evidence that these are in a continuum that results in those conditions or FASD. Now in the planning stages, this will be multi-disciplinary, multi-site collaborative research project.

Public Comment: None.

With no further comment, the meeting adjourned at 5:06 p.m.

DECEMBER 7, 2004

Updates, Continued

American Academy of Pediatrics: Dr. Brenneman reported on findings from the CDC-AAP physicians survey regarding alcohol consumption during pregnancy and FAS. Of 48,000 questionnaires mailed to AAP members, 55% responded. Regarding knowledge, training, or expertise to care for children with FAS, 77% reported lacking the needed knowledge or training, and 29% lacked the time. While their knowledge of FAS' features and its epidemiology was good, they were less prepared to diagnose, manage, and care for a patient with FAS. A report will be published in *Pediatrics* in the next several months. The role of pediatricians in primary prevention is clear. But while they are good at closing opportunity gaps such as missed immunizations, their ability to do so at the adolescent visit was less certain. Communication with mothers is helpful to enable counseling and testing to determine children's cognitive problems and then to find interventions.

NOFAS: Ms. Mitchell reported that NOFAS now has four affiliates (South Dakota, Minnesota, California and the United Kingdom). With support from the FASD Center for Excellence, they plan to bring on four more (Alaska, Oregon, Washington state and Connecticut). Soon, NOFAS will also issue materials developed with CDC for use in K-12, along with an advocacy guide. They are continuing to work with the Cherokee Nation as well.

American College of Obstetrics and Gynecology: Dr. Sokol indicated that CDC and ACOG are working together to advance OB/GYNs' understanding of how to screen women for alcohol use and how to conduct brief interventions in order to prevent alcohol-exposed pregnancies. A related conference call will be set up between Drs. Sokol, Chapin, and Floyd in the next week to discuss this. Dr. Chapin is also in the process of obtaining ACOG endorsement of the recently published FAS Guidelines. This will also be discussed during the conference call.

March of Dimes: Ms. Antrobus, representing Karla Damus, reported on the MOD's campaign on prematurity. It focuses on preterm birth (PTB), the rates of which have risen since the 1980s, to comprise 12.3% of all births in 2003. It is the leading cause of perinatal and neonatal mortality in the U.S., the second leading cause of infant mortality and the leading cause of black infant mortality. The campaign goal is to reduce PTB to 10.1% by 2007 and to 7.6% by 2010. Infant mortality steadily declined to the year 2000, then again increased slightly. Birth defects were the leading cause of infant mortality in the 1990s. PTB was second but gained in 2002. The previous belief that 75% of all preterm births were preterm labor has given way to a new understanding that there are three different categories of PTB. Currently, ~33% of births fit into one of these definitions: spontaneous preterm labor, medically indicated premature membrane rupture, and medically indicated PTB. The latter is an emerging trend.

The factors involved with PTB include the type of PTB, maternal age, race, ethnicity and plural births. Teenaged mothers lead the rates of PTB; and while blacks lead ethnically, that began declining in 2001 as other groups' rates increased. The MOD Perinatal Data Center map the U.S. PTB incidence by state and county, showing the south with the highest clusters, and Nevada in second place.

The top four PTB risk factors include: multi-fetal pregnancy, history of PTB, mid-trimester bleeding; and uterine, cervical or placental abnormalities. Others include maternal age, black race, low SES, unmarried status, previous fetal or neonatal death, \$3 spontaneous terminations, uterine abnormalities, incompetent cervix, genetic predisposition, obesity, low pregnancy weight, bleeding, anemia, stress, lack of social support, tobacco, alcohol and drug use, and folic acid deficiency. The prime time to address most of these factors is before conception or between pregnancies, since many cannot be addressed during pregnancy.

Factors contributing to the rising PTB rates are the rising age of women delivering at \$35 years, the rising rates of multiple births, indicated deliveries, inductions, and enhanced management of maternal and fetal conditions, patient preference (demanding C-sections or inductions), substance abuse, bacterial or viral infections, and increased stress. The rates of the first four continue to rise, and many of the women with asymptomatic bacterial and viral infections remain untreated.

The MOD's history of involvement in PTB issues was outlined, as were its current grants, initiatives, and programs. Data from the MOD perinatal epidemiological research grants (1998-2004) and other research identified several major causes of PTB: inflammation and infection, stress and fetal stress/bleeding, and stretching with uterine

distention. The MOD Scientific Advisory Council has defined PTB as a Common Complex Disorder. It is common in that it effects over 12% of births, and it is complex in that its phenotypes are not of Mendellian segregation patterns and/or assortment, but exhibit a preferential familial clustering that cannot be explained by cultural or environmental causes. There are genetic contributions, environmental influences, and gene/environment interactions. Genomic approaches add to community-based interventions, consumer and provider education.

MOD's prematurity campaign includes a focus on equity in health outcomes and healthcare. The campaign's goal is to "Prevent the Preventable" -- unintended pregnancy, inadequate folic acid levels, extremes of weight, tobacco/drug use, use of some prescription drugs, environmental toxins, known genetic/familiar risks, etc., that result in PTB. With \$75 million to invest in the next five years, the MOD will aim outreach to those at risk, with signs/symptoms indicating the possibility of a PTB; to provide support to families with a PTB baby; and to increase awareness of PTB among the public. Focus groups indicate that few consider it to be a problem.

CDC: Dr. Floyd reported that CDC has funded FAS research and prevention activities since 1991. CDC has worked to establish state-based FAS surveillance systems and has monitored alcohol exposure rates among childbearing age women through the BRFSS. CDC has also tested approaches that intervene with women at risk for an alcohol-exposed pregnancy along with community-level prevention strategies, such as provider education and public awareness campaigns.

Dr. Floyd described the recently funded FAS Prevention projects. In 2003, five states (Missouri, Minnesota, Michigan, the Dakotas and Colorado) were awarded grants. Two additional states were added (Oregon and Wisconsin) in 2004. These projects have multiple components, including setting up FAS surveillance systems (using the FASSNET methodology as its framework), monitoring alcohol consumption, developing individual and community-level interventions for women at risk for an alcohol-exposed pregnancy, and linking children to services. Two new research projects were funded (St. Louis University and Nova Southeastern University) to explore the development and evaluation of self-guided change community-based approaches. The Nova project is an adaptation of an approach used in Toronto, where advertisements asking, "Thinking of Changing Your Drinking?" solicited calls to a hotline which randomized participants into two groups: one received assessment and a counseling intervention while the other received assessment and an educational brochure. Both approaches did well and the brochure approach was less costly. This model is being adapted and tested to target women at risk for an AEP. Dr. Mengel's project is comparing self-guided change interventions (regular mail vs. Web-based) targeting African-American women in St. Louis, with a comparison group in Kansas City. The intervention is similar to Project Choices, either reducing drinking levels, increasing effective contraception, or both.

The FAS Team is analyzing Project Choices and the preliminary analysis will be presented to NCBDDD in January 2005. Abstracts will be submitted for publication to disseminate the results. As mentioned by Dr. Sokol, work will continue with ACOG on screening and brief interventions.

Dr. Ebrahim reported that Dr. Godfrey Oakley and he had attended the Consensus Global Meeting on Disease Elimination and Eradication. The candidate conditions being reviewed were primarily infectious diseases. However, they submitted folic acid levels for consideration on the consensus group's agenda, and met their criteria. Having FASD on the global agenda is important for policy purposes, and it may be another candidate condition to consider for elimination.

The Role of the Medicaid Program on Screening Women for Substance Use and Identifying Children with Prenatal Alcohol Exposure

Mr. Richard Fenton, Deputy Director of Centers for Medicare and Medicaid Services' (CMS) Family and Children's Health Programs Group, presented an overview of the Medicaid program as it relates to women and children. The Medicaid program is a federal/state partnership. CMS assures that certain minimal requirements are met in all states and allows flexibility in how the state administers its program. State Medicaid programs are reviewed and approved by CMS, but the state retains program control. As a result, there is a great deal of variability of what the states offer above the minimum CMS requirements. CMS pays a 1:1 match, sometimes up to 65% of the state investment. Some states require special waivers (e.g., Section 1115) to expand their coverage beyond the traditional Medicaid parameters. This can exceed the standard amount paid by the federal government for the program as long as it is budget-neutral. States do that by using managed care options. This option could provide cost savings allowing additional coverage. Most of these additional beneficiaries are the male member of the family as well as families not covered under the AFDC population.

Of the country's 44 million Medicaid beneficiaries, 75% are women and children. The other 25% are those who are disabled or elderly and, although these groups are the minority in number, these constitute most of the program's costs. Where 16% of state budgets were historically used to fund Medicaid, it now generally takes up over 20% of the state budget. When Medicaid moved from an opt-in program to an entitlement, it became hard for the states to cut back. To control costs, the states are asking for federal waivers and looking for ways to save while implementing state programs. In the meantime, they are continuing to cover the costs with whatever resources are at hand.

New York, California, and Texas have the highest Medicaid expenditures (the federal and state matches in 2002 were \$36 billion, \$27 billion, and ~\$13 billion, respectively). The lowest expenditures were in Wyoming at \$274 million and the Dakotas and Montana at ~\$500 million. Mr. Fenton reiterated several times that Medicaid is growing and the states are trying to cover costs and/or reduce benefit packages.

Minimum eligibility requirements for the states are in several categories:

1. *Categorically needy*: This includes those under AFDC (now known as TANF – Temporary Assistance for Needy Families), children <6 years old, and pregnant women, with a minimum requirement of up to 133% of the federal poverty level. For children aged >6 years, the states cover benefits up to 100% of the federal poverty level. States can also cover up to 185% of the federal poverty level with

the full benefit package, or even higher with “income disregards” that allow the states to disregard some income.

2. *Medically needy*: This category in 37 states is for those with more income than allowed in Category #1. This category requires coverage for and services to pregnant women. Benefits/services include a) pregnancy and pre-/post-natal services and b) 60 days of postpartum services for those <18 years old. Additional optional state services are listed on the CMS Website.

Covered services include the following:

- Mandated inpatient and outpatient hospital service benefits which cover early periodic screening, diagnosis and treatment (EPSDT), family planning services and supplies, physician services, medical and surgical dental services, home health for beneficiaries entitled to nursing facility services under the state plan, nurse-midwife services, pregnancy-related services and services for other conditions that may complicate pregnancy, and 60-days postpartum pregnancy-related services
 - Pharmacy services are not automatically included, but all states have opted to include this. It is one of a range of services that are optional, beyond the mandatory ones that must be covered to assure that 90% of people needing treatment get it. The states’ definition of how the mandated services are provided is very flexible.
3. *EPSDT* is a covered benefit to children up to age 18 years and is optional to age 21. This covers all Medicaid services even if the child is not enrolled in the state plan, as long as the services are determined by a physician to be medically necessary. This is considered the “Cadillac” of Medicaid health plans for the poorest children.
 4. *S-CHIP* (State Children’s Health Insurance Program) programs have provided supplemental medical insurance since 1998 for children whose family has too much income for them to be eligible for Medicaid. It covers income up to 200% of the poverty level and is a voluntary program in which all states participate. The states are given an allotment each year that they can spend over two years. S-CHIP provides a higher match (at 65-85%) than does Medicaid (50-65%) and is also more flexible. It either expands the Medicaid program or provides coverage by using other health insurance programs (e.g., Blue Cross/Blue Shield or a large HMO). Actuarial tables are used to determine the package, or a Secretary-approved package can be used. The state can provide waivers to cover some additional children’s family members, as Medicaid does. Recently, six states elected to cover prenatal services for the unborn as a way to provide services to illegal immigrants.

Discussion included:

- *Is EPSDT covered under S-CHIP?* It is included if the state decides to do so. If they do not, the children get coverage that is comparable to other health insurance programs and immunization services. The biggest expense involved is that for

treatment. The state's options are to include or expand the program, or go to a separate program. Some states do both.

- *In family planning services for the categorically needy, any women covered by Medicaid can see a doctor to get contraception; and since all states adopted the pharmacy coverage, can they get contraception?* Yes. Family planning actually is paid at a higher federal match. There also are family planning waivers to cover postpartum costs for women, some eligible to 60 days, at up to 185% of the poverty level. The child is eligible for one year whether or not the mother is. The waivers for family planning services are to help the women not become pregnant again. The budget neutrality test is passed by the saved costs due to averted births.
- *Are EPSDT medical or behavioral services covered when diagnosed by physician with an ICD-9 or -10 code?* As long as it is for medically necessary treatment, as defined by the state, the child should receive services. That has to be determined state by state. The Georgia AAP's Committee on Child Financing created a table of what services are covered by EPSDT, state by state.
- *How does Medicaid/S-CHIP identify the mothers drinking during pregnancy, or children who may be at risk?* States are implementing managed care. The potential mother needs to be enrolled in Medicaid. However, in some states eligibility only occurs with pregnancy. For pregnant women, some states have presumptive eligibility when a physician identifies the woman as eligible and then the paperwork follows. That is another state option.
- *Does the EPSDT intake form have any specific questions about prenatal exposure to alcohol?* There are no questions on the intake form on exposure to alcohol. This is at the states discretion.
- CMS allows the states to use their own clinical criteria and guidelines to provide services within specific service areas. This is true. This kind of flexibility both hurts and helps. With the states' need to save money, if something can demonstrate savings, it will be done and other states will follow. CMS is comparing all the states' cost-saving methods, such as the use of managed care. If identifying a child as prenatally exposed to alcohol, or if using contraception to reduce alcohol-exposed pregnancies were shown to result in a cost saving to the program, they would be done.
- *So is CMS open to the idea, if supported by data, to recommend to states that they should screen for alcohol use and identify children who may be affected by prenatal alcohol exposure?* A new CMS Division is being set up to share the states' best practices and quality issues. Those will be shared through the Web or at various meetings, etc. It is expected that those guidelines will be adapted if they show savings, especially if coupled with demonstrated quality.
- Dr. Wright had never seen EPSDT as a way to get children into services and she did not believe managed care to be a solution for Medicaid's problems. Georgia also has proposed a \$400 million cut in Medicaid despite the fact that every dollar cut loses \$14 in a federal match. How services can be saved is far from clear. Screening is poorly reimbursed historically; the funding goes to sick visits. Medicaid admittedly has been a notoriously poor payer. All the states are at a loss as to how to balance their budgets. Where 10 years ago, budget neutrality was seen as the

way to save, any present analysis would have to involve sheer guesswork as to potential savings. Decreasing the reimbursement for the office visit essentially decreases access. Pediatricians cannot afford to make up the difference. But it also is hard for the federal government to determine what “access” is, or to evaluate if it is affected. The only, and very small, “stick” available is to not pay for services unless they are increased, but that does not help anyone much.

- There is also a problem with coverage for adults with FASD, and Medicaid’s lack of coverage (e.g., in Maryland) for adult dental services. Few providers want to see a Medicaid patient and the waiting lists are long. These are problems. Adult dental coverage is optional. Dr. Floyd commented that one answer may be, as done long ago in Georgia, to train health department nurses to provide EPSDT services. That identified many children with anemia and provided entry into the system for services.
- Under the fee for service system, physicians were more willing to provide health care, but now the “medical home” concept is encouraged. New Jersey has a good well-baby care program, but many physicians do not submit for EPSDT reimbursement because they perceive little difference in the services the child will receive and because of the time needed to complete the forms. The real difference has occurred in specialty care (e.g., physical or occupational therapy) where professionals able to file for Medicaid reimbursement are hard to find.
- Dr. Wright suggested checking what the recommendations of AAP and ACOG are with regards to EPSDT.
- The NJ FASD Task Force asked their Medicaid program to add prenatal alcohol screening as a standard of care for prenatal care and preconceptional health care screening. They may well do it, since the cost to add 5-6 questions to the screen is minimal. The question is how do we as a national Task Force want to approach state Medicaid offices to promote alcohol screening as a standard of care?
- The future savings from providing juvenile mental health care could be considerable, but that estimate has not been done. Medicaid collaboration with the NIMH and the Department of Justice would help. Studies demonstrating cost savings in this arena should be considered. Again, states are struggling to pay their bills, but they can be made aware of best practices. Dr. Wright suggested providing the states with the best practices in FAS prevention (e.g., screening) and intervention (e.g., early identification) outlining the potential for positive service outcomes and cost savings.

Presentation on Person-First Terminology

Presenter: Ms. Melinda M. Ohlemiller

In response to a request by the Post-Exposure Workgroup, Ms. Ohlemiller reviewed the appropriate terminology to describe persons with disabilities. Language either joins or separates. Person-First terminology uses the person first followed by the descriptor (e.g. children/boy/girl with FASD). While this can be cumbersome at first, it eventually flows naturally in conversation. It is also encouraged not to add a descriptor if it is not necessary. Language “don’ts” include such usage as “FAS children” or “FAS-adults;” “special needs children” or “sickle cell child.” People are not defined by their disability;

they “are” not FASD. The words with dignity are always used first. For example, rather than “women using/abusing alcohol” or “chemically dependent women”, “women who use/are dependant upon alcohol” would be used. Ms. Ohlemiller also preferred the term to “alcoholic.” When asked, she declined to apply these rules to sexual orientation, as this is not a disability. However, CDC does use the term “men who have sex with men” (MSM). While practitioners will use certain terms within their own settings, these should never be used when interfacing with the public. Families do notice when person-first language is used and that is an instant rapport-builder. Person-first terminology is simply good common sense.

Workgroup Reports

Dr. Cohen provided the **report of the Post-Exposure Workgroup**. The group reviewed the revised draft of the mission statement and several minor changes were made. Drs. Brenneman and Carmichael Olson updated the group on progress to date on efforts to include FAS in the DSM5. Dr. Brenneman spoke with an APA fellow who has had experience with the DSM committee. Ms. Gass indicated that Robert Fletcher is involved in the DSM5 chapter called “Behavioral Phenotype of Genetic Disorders” and is interested in including FAS. Callie will follow up with Dr. Fletcher on this. The workgroup acknowledged that FAS could be included in several sections of the DSM5 so an ad hoc group was formed to identify and share this information.

Since the reauthorization of IDEA has passed, the workgroup will draft a letter to the Department of Education regarding the inclusion of FAS in the list of conditions outlined in the IDEA regulations. They recommended that the letter be endorsed by members of the Task Force before being sent to the Secretary.

The workgroup recommended that consultants be engaged to help them develop a research agenda focused on interventions for children and families. For the next Task Force meeting, it was suggested that workgroups meet for a full day with the consultants, and that Task Force business be conducted on the second day. This would provide more time for the workgroups to deliberate on and plan their activities. Dr. Floyd added that CDC could also arrange for workgroups to have in-person meetings in between the formal Task Force meetings.

A **report for the Prevention Workgroup** was provided by Dr. Miller. The workgroup discussed Dr. Caetano’s research findings and Dr. Babor’s matrix, which were both presented yesterday to the Task Force. They discussed how to flesh out the matrix and talked about the outlined strategies as they relate to the prevention of alcohol-exposed pregnancy. The group also brainstormed on key principles to consider in determining which strategies would be most relevant and effective in FAS prevention. Some of these factors are:

- Strategies should be based on evidence-based approaches or best practices. What is the current evidence? What target populations are at greatest risk? What is the cost/benefit of the selected approaches?
- Strategies covering the spectrum of interventions (population level – client level) and a range of target groups should be considered.

- There is an understanding that various prevention strategies working simultaneously could have a synergistic effect.
- There is a consideration for cost (cost of interventions, dollars saved, etc) and priorities for funding strategies and interventions.
- Strategies should be sustainable. Need to assure that interventions/activities will remain after the government funding ends.
- Consideration should be made of the possible side effects that may result from implementing certain recommendations (i.e., taxation policies).

A follow-up conference call or meeting of the Prevention Workgroup will be held. June 2005 is the target date for completion of the workgroup's preliminary report.

Dr. Floyd added that each workgroup could meet, perhaps in three months, depending on the volume of its work and member availability.

Public Comment: None.

Closing Comments

Date options for the next meeting will be circulated via email to the members. Factors affecting the date included the meetings of the Research Society on Alcoholism (June 25-30) and the FAS Study Group (June 25); the New Jersey Governor's Council meeting in early June; and Mr. Schad's travel to Europe (May 15-30).

Drs. Wright and Floyd thanked all those who attended the meeting and the meeting adjourned at 11:55 a.m.

Minutes approved on 4/12/2005
By Jean A. Wright, MD
Chair, National Task Force on FAS/FAE

Attachment #1: IOM Funnel Risk/Intervention Diagram

Women 18-44 Pregnant and Non-Pregnant at Different Levels of Risk and Potential Interventions

